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EXPLORING RECOVERY IN WOMEN DIAGNOSED WITH
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Section A

Abstract

Until recently the social context of the mental health needs of women in secure units has not been given sufficient consideration. Compared to men, women in secure units are more likely to have been looked after children, experienced sexual abuse, use self harm as a coping strategy and have been given a diagnosis of BPD.

Historically BPD is one of the most stigmatising mental health disorders but more recent studies examining clinical symptoms, indicate a more positive prognosis for clinical recovery. Currently personal recovery has been emphasised, defined by service users and viewed as a journey. Recovery principles are being applied in secure settings – seen by some as antithetical to recovery - due to restrictions on self determination and meaningful occupation.

Three papers have explored secure recovery from the perspective of, mainly male, service users diagnosed with schizophrenia but there is a significant gap in the literature with respect to personal accounts of recovery for individuals diagnosed with personality disorder, and women in secure settings.

Qualitative research exploring how women diagnosed with personality disorder in secure settings understand their recovery, and the factors that support and undermine this, would contribute to the development of a recovery approach specific to this population.

Introduction

The aim of this review is to explore the concept of recovery and its relevance for women who have been detained in a secure setting and diagnosed with a personality disorder.

The review will start by considering the issues and contributing factors pertinent to women's mental health generally. It will present the arguments for why the mental health needs of women detained in secure settings are different to those for men. Given that many of these women will have been given a diagnosis of personality disorder (PD) – most commonly – Borderline Personality Disorder (BPD), the review will, briefly, discuss the diagnosis and examine the current literature on recovery and BPD.

The concept and origins of personal recovery will be introduced and the challenges of applying recovery principles in secure settings will be explored. Existing qualitative accounts of recovery in secure settings will be reviewed and issues specific to women with a personality disorder diagnosis in secure settings will be considered.

The review will conclude by identifying gaps in the literature and recommending areas for further research.

Women and mental health.

In 2002 the Department of Health published 'Women's Mental Health: Into the Mainstream'. It was heralded as evidence of the government's commitment to tackling acknowledged gender inequalities in the delivery of mental health services (DoH, 2002).

It highlighted that, compared to men, women were more likely to experience anxiety, and depression (Gold, 1998) and that the most significant risk factors for mental health problems

amongst women were poverty (Acheson, 1998; Oppenheim & Harker, 1996), physiological factors (NICE, 2001), life events (Brown, Bifulco, & Harris, 1997) and social isolation (Arber & Ginn, 1995; HMSO, 1998). Jeffcote and Watson (2005) wrote that although women tended to have better social networks than men, which could serve to protect against mental ill health, when the ability to form and maintain meaningful relationships was impaired some women had few other sources of support and were more likely end up in the mental health system.

The report also concluded that violence and abuse, disproportionately experienced by women, were most devastating to mental health. Prevalence studies suggested that women were three times more likely to be sexually abused than men (Bolan & Scannapieco, 1999; Finkelhor, 1994). Between 18-30% of women had experienced domestic violence (Dobash, 1992; Cleaver, Unell, & Aldgate, 1999) and 14-40% had been victims of sexual violence (Myhill & Allen, 2002). The report also considered the specific needs of women in secure and forensic services - the differences in the social and offending profiles of men and women are outlined below.

Women in secure settings

Women in secure settings found themselves marginalised in a system primarily designed for men and comprised only sixteen percent of the medium secure population (DoH, 2002).

Compared to men, women in secure settings were more likely to have been detained under the civil section of the mental health act, have a history of arson as opposed to direct acts of violence against the person, have a history of abuse and self harm, have physical health problems and been diagnosed with BPD (Home Office, 1999). Women were often kept in higher levels of security than they actually needed, given that in general, they were less likely to abscond and posed less of a risk to the public (Coid, Kanton, Gault, & Jarman, 2000).

It was recommended that: women's secure services be provided in single sex settings; a range of inpatient services be provided to meet the needs of women with complex needs (such as BPD); options to participate in mixed sex activities be offered as part of a recovery based approach; and high support community placements be developed alongside secure units.

Bartlett (2003) commented that although the report was heavily influenced by medical models of mental health the attempt to expand its remit to incorporate social identity was to be welcomed. While she applauded the emphasis on gender issues and the incorporation of service user views and experience, she criticised the restriction of the report to working age women and the failure to call for research into effective treatment models.

Nevertheless the findings echoed those from an earlier study commissioned by the charity Women in Secure Hospitals (Stafford, 1999) to explore the differences between men and women detained in secure hospitals. Analysis of case-registers revealed that women were more likely than men to have been looked after children, have experienced sexual and physical abuse, to have never been employed, have a history of alcohol dependency, to be detained under Part III of the Mental Health Act (civil section), to be diagnosed with a personality disorder (predominantly BPD), to engage self harm, and to have been admitted due to damage to property, suicidal and self harm behaviour, and aggressive behaviour towards staff.

The report called for these women to be understood within a social context where there continues to be gender inequality and recommended that assessment focus, not just on individual pathology but, the social and economic contributors to mental distress. It emphasised that women with a diagnosis of BPD may find secure hospitals particularly difficult to cope with as they are surrounded by other patients exhibiting high levels of distress and are subject to a discipline regime rooted in custodial model. The women's affect

vulnerability, lack of self identity and sense of powerless were seen as likely to be exaggerated in secure units and could lead to more incidents of self harm and assaults against staff (Stafford, 1999)

A subsequent qualitative study explored 56 women's views and experiences of secure settings (Parry-Crooke, 2000) and the final report 'Good Girls: Surviving the Secure System' highlighted two main issues: firstly, women did not feel respected by staff and were not enabled to participate in an informed way about any aspect of their care; and secondly, that the women needed to 'toe the line' – to take their medication, take part in therapy and obey the rules. Thoughts of challenging aspects of their care had to be weighed against the possibility that this would be construed as lack of compliance and could affect their discharge date.

The Corston Report (Home Office, 2007), commissioned after the suicides of six women over a 13 month period at HMP Styal, also emphasised the role of social, personal and economic factors in women's offending, the high level of mental health difficulties of women in prison and the need to replace women's prisons with small, multi-functional, geographically dispersed custodial centres.

A 2009 audit of women's medium secure services suggested some progress had been made (Parry-Crooke & Stafford, 2009). It identified 27 dedicated women only medium secure services, providing 543 beds, compared with only 14 beds in 2000. Nineteen of these services had a gender specific care pathways linked to women only rehabilitation services. Staff and service users were aware of the need for relational security and there was increased provision of therapeutic services to support women in developing an awareness of their own mental health needs.

Adshead (2005) took the slightly different position that male and female offenders were more alike than they were different and that gender didn't adequately differentiate between individual service user needs. She warned that focusing on gender obscured important psychological differences, leading to discriminatory practice and unfair allocation of resources. She argued against viewing male violence as nasty but normal and female violence as requiring special explanation based on experiences of trauma, stating that, while violence may be a reaction to suffering, this applies as much to men as it does women.

However what seemed clear is that the individual needs of women, including those related to their gender, had been subsumed in a system dominated by the needs of the male majority. Broadly speaking the attempts to develop gender specific services had been welcomed. It may be contended that an agenda that recognises the links between childhood adversity and social deprivation, and, mental illness and offending may ultimately serve to promote a better understanding of the needs of men and women in secure settings.

As previously stated, many women detained in secure settings will attract a diagnosis of PD, most commonly, BPD. In the next section the meaning of this diagnosis and the existing research on recovery from BPD will be reviewed.

Personality Disorder

DSM-IV defines personality disorder as: 'an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment (APA, 1994). Studies indicate a prevalence of 10-13% in the adult population equally distributed between genders (NIMHE, 2003), however women are far more likely than men to be given a diagnosis of BPD. DSM-IV estimates that women

are diagnosed at a rate of 3:1 compared to men (APA, 1994) but it is unclear whether this reflects actual prevalence or is due to diagnostic biases

Borderline Personality Disorder

DSM-IV describes the key features of BPD as instability of interpersonal relationships, self image and affect combined with marked impulsivity (APA, 1994). The aetiology of BPD is unclear but is thought to be due to a combination of genetics (Torgensen, Lygren & Oien, 2000), neurophysiology and neurobiology (Rusch et al 2003; Coccaro, Lee & McCloskey, 2003), psychosocial history of abuse and neglect (Zanarini, Frankenburg, Reich, & Silk, 2000) Horwitz, Widom, McLaughlin, & White, 2001) and disrupted attachment systems (Lyons-Ruth, Yellin, & Melnick, 2005).

Historically BPD is one of the most contentious and stigmatising mental health diagnoses with individuals reporting being routinely described as manipulative, attention seeking, difficult and untreatable (Haigh, 2002). The reliability and validity of the diagnostic criteria have been heavily criticised (Tyrer, 1999) as diagnosis is frequently made on the basis of subjective judgments about the patient's presentation and descriptions of their difficulties (Western, 1997). Given its association with trauma, there have been calls to reclassify it as a form of complex Post Traumatic Stress Disorder (PTSD: Yen & Shea, 2001).

Despite these concerns over the last couple of decades the evidence base for effective treatments for BPD has been growing and now include Mentalisation Based Therapy (Fonagy & Bateman, 2007), Cognitive Analytic Therapy (Ryle, 1990) and Dialectic Behaviour Therapy (Linehan, 1993). Aspects of these therapies, as well as the use of therapeutic communities for people with personality disorders, serve to promote self responsibility, a key component of personal recovery models which will be discussed later.

Personality Disorder and Recovery

The DSM-IV and ICD-10 definitions of personality disorder emphasise the stability of the construct over time which would appear to contradict the idea of recovery. However longitudinal outcome studies of people diagnosed with BPD indicate a more positive prognosis than previously expected (Stone, 1993).

Karaklic & Bungener, (2010) conducted a literature review of outcome studies to explore whether attitudes to the treatment of people diagnosed with BPD had become more optimistic. A number of retrospective studies of 15 year outcomes for individuals diagnosed with BPD indicated significant improvement over time (Plakun, Burhart, & Muller, 1985; McGlashan, 1986; Paris, Brown, & Nowlis, 1987; Stone, 1990) with mean scores on the Global Assessment of Functioning (GAF: Endicott, Spitzer, Fleiss, & Cohen, 1976) scale falling within a mild range of impairment. A 27 year retrospective study showed that only eight percent of individuals continued to meet the threshold criteria for a diagnosis of BPD (Paris & Zwiig-Frank, 2001). However retrospective studies are limited by the influence of confounding variables and selection bias.

Two prospective studies (Skodol et al. 2005; Zanarini, Frankenburg, Hennen, Reich, & Silk, 2005) demonstrated a more rapid reduction in severity of symptoms than had been expected, with 75% of individuals diagnosed with severe BPD no longer meeting the diagnostic criteria after six years. In a follow-up to latter study, Zanarini, Frankenburg, Reich, & Fitzmaurice (2010) examined the time to attainment of recovery from BPD and its subsequent stability in a 10 year prospective follow-up study. Recovery was defined as a GAF score above 61 (mild

symptoms). The individual also had to have at least one emotionally sustaining relationship and be able to work full time.

The results showed that 50% of participants achieved full recovery but that more than 90% participants experienced symptomatic remission over a 2 year period. This suggested that good social and vocational functioning was harder to achieve than reduction of symptoms. The study was limited by the fact that all participants were initially from inpatient facilities and therefore were more likely to have severe symptoms possibly making psychosocial rehabilitation more difficult compared to individuals in the community. Furthermore most of the participants were in treatment over the course of the study so the results may not generalise to untreated populations. The authors concluded that psychological treatment of individuals diagnosed with BPD had focused too much on symptom reduction and risk management and recommended a refocusing on the promotion of good psycho-social functioning, which was likely to be more meaningful for the service user.

While this evidence highlighted that people diagnosed with personality disorders could improve and get better, little light was shed on the mechanism by which this occurs. Furthermore the term recovery utilised by these studies referred to clinical recovery - described by Slade (2010) as clinician defined and focused on the remission of symptoms. There was no sense of how recovery would be defined by the individuals themselves. Slade argued that the goal for mental health services was to change the focus from clinical recovery through treatment to personal recovery by the promotion of well being. The concept of 'personal recovery' will be explored in the next section

Personal recovery in mental health

Historically the recovery approach in the UK dates back to the late 18th Century and the Tuke Retreat in York (Roberts & Wolfson, 2004). More recent manifestations of personal recovery

within mental health services arose from the service user movements of the 1980's and 90's in the United States and the United Kingdom. Service user accounts of coping, getting better and developing an identity distinct from their mental health problems have contributed to the concept of personal recovery (Deegan, 1988; Coleman, 1999).

Although there is no universally accepted definition of recovery in the arena of mental health Slade (2010) stated that personal recovery is self-defined, emphasises hope, identity, meaning and personal responsibility and assumes that there are many roads to recovery. A widely cited definition of personal recovery was provided by William Anthony (1993) who defined it as:

A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful and contributing life even within the limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. (p.13)

Repper and Perkins (2003) advocated viewing recovery as a journey and stated that:

Recovery is not about getting rid of problems, but about seeing people beyond their problems, their abilities, possibilities, interests and dreams, and recovering the social roles and relationships that give their life meaning. (p.ix)

Numerous models of recovery have been proposed drawing on qualitative research exploring recovery from schizophrenia. Some have attempted to identify the domains of recovery (Spaniol, Gagne, Koehler, 1997; Ralph, 2000; Lapsley, Nikora, & Black, 2002; Andresen, Oades & Caputi, 2003) whilst others have outlined possible stages of recovery (Davidson & Strauss, 1992; Baxter & Diehl, 1998; Young & Ensing, 1999). A limitation of the stage model is that it could be seen to suggest what 'should' happen as it attempts to bring order to the

chaos of human experience. Nevertheless it may help to develop therapeutic optimism, aid with making sense of progress and lack of progress, and assist the clinician in providing support that is appropriate to the stage of recovery (Slade 2010).

The recently devised Personal Recovery Framework (PRF) attempted to elucidate the mechanisms by which recovery may occur (Slade, 2010). Rather than be prescriptive it provided guidance to mental health professionals about how best to support recovery and identified four tasks of personal recovery: Firstly, the development of a positive identity outside of the illness, as well as the ability to differentiate the self from the diagnosis - which has been associated with better outcomes (Davidson & Strauss, 1992); secondly, the development of a meaningful understanding of the experience of mental illness; thirdly, to make the transition from being clinically managed to assuming personal responsibility through self management. The final task involved reclaiming previous roles and the development of new, socially valued roles. All four tasks involved relationships with family and friends, other service users, specific mental health professionals or with a higher being.

Although recovery approaches originated within the grass roots service user movement it has been increasingly adopted across the world, most notably in New Zealand, the U.S. and the UK. Policy documents such as 'Making Recovery a Reality' (Shepherd, Boardman, & Slade, 2008); 'A common purpose: Recovery in future mental health services' (CSIP, 2007) and the NIMHE Guiding statement on recovery (NIMHE, 2005) indicate the increasing commitment of the UK Government and Department of Health to recovery based approaches in mental health.

However, criticisms of the approach have been voiced by service users who are concerned that recovery principles are being used to justify withdrawing services, cutting benefits and coercing people back into work (Shepherd , Boardman & Slade, 2008). There are also

worries that the ‘professionalisation’ of recovery could result in the person centred, empowering aspects of recovery being lost (Slade, 2010). Meanwhile studies by Davidson, O’Connell, Tondora, Styron, & Kangas, (2006) and Shepherd, Boardman, & Slade, (2008) indicate that professionals are concerned that recovery may be an unrealistic proposition for many service users, colludes with denial of the illness and does not take account of the need to manage risk. Whatever the reservations, support and recovery teams and recovery plans are now commonplace in mainstream mental health services.

Personal recovery approaches have been developed in the field of schizophrenia (Bonney & Stickey, 2000) and are now being used with other severe mental health disorders including personality disorder. The revised NICE guidelines for working with BPD (NICE, 2009), the document ‘Personality Disorder: No longer a diagnosis of exclusion’ (NIMHE, 2003) and ‘The personality disorders capabilities framework’ (DoH, 2003) have a clear recovery based orientation. Nehls (2000) advocated a recovery based approach for individuals with a diagnosis of borderline personality disorder, emphasising the need to believe that recovery is possible. She highlighted the requirement for genuine partnership between service users and staff.

However, given that recovery is essentially a social process (Schon, Denhov, & Topor, 2009) and individuals with diagnosis of personality disorder often experience significant difficulties in interpersonal relationships one might predict that transposing a model of personal recovery, developed primarily in the context of psychosis, onto work with individuals with personality disorder could raise some challenging issues. This will be considered later in the review.

First the tensions and challenges of applying personal recovery principals, primarily developed in community populations, to work in secure settings will be examined.

Secure Recovery

There is limited evidence regarding the applicability and value of recovery approaches in secure settings (Turton, et al 2009) which are, by their nature, contradictory to recovery principals. Merzey, Kavuma, Turton, Demetriou, & Wright (2010) asserted that legal detention compromised the capacity to exert choice and control over treatment and long periods of time spent in secure could undermine hope and optimism and the promotion of self care and independence. Furthermore if the individual had committed an offence the treatment approaches would involve challenging and confronting rather than affirmation and acceptance.

In an unpublished service document, Alred and Drennan (2007) outlined a model of recovery for application in a secure setting. They described the challenge of integrating recovery with a duty of public protection and the tension between the development of a client centred relationship and the fact that individuals were being held against their will, where their movement is restricted and they may not have access to meaningful occupation.

Four conditions were identified as being essential for promoting recovery in secure settings: firstly, the creation of a sense of community and the development of a therapeutic environment which could provide opportunities for attachment, containment, communication, involvement and empowerment (Campling & Haigh, 1999); second, access to meaningful occupation to support the formation of personal and social identity; third, access to therapy based on a thorough assessment where medication may form part of treatment alongside education about its side effects and potential benefits; finally, relational security was emphasised for the safety of service users and staff which could be promoted through attachment relationships, containment and consistency (DoH, 2007). The document

highlighted the need for proper staff training and support, and advocated increased service user involvement in the running of the unit.

However, the document focused only on individuals who had committed an offence and did not consider the specific needs of women or how best to address the issue of self harm within a recovery approach. Furthermore it did not convey how the service users themselves define and understand their own recovery. To date only three published studies explore how individuals with severe mental health problems, detained in secure units, define and understand their own recovery. These are reviewed below.

Qualitative research into secure recovery

Lathwaite and Gumley (2007) published the first qualitative study exploring service users' views on recovery in a forensic high secure unit. They interviewed twelve men and one women with a diagnosis of schizophrenia using semi structured interviews that were then analysed using social constructionist grounded theory. They found great contrasts between the accounts with some being rich in detail and highly reflective and others being short and unelaborated. They hypothesised that the difference in reflective capacity may be explained by different attachment experiences (Foneyg, 2001) and could possibly be used to predict risk. However one might also summarise that the differences between accounts reflected the fact that different participants were at different stages of recovery.

All participants spoke of the importance of relationships with family and staff, and the adverse life circumstances that led to them being in hospital. Questions about experience of recovery within the context of a secure hospital revealed themes of fear versus safety, feeling entrapped, coping, meaningful outcomes and the development of trust. It emerged that for service users - recovery was less about the remission of symptoms and more to do with symptom reduction and better managing the effects of being a patient in the mental health

system. The study was limited by the fact that the researcher was known to participants which may have affected confidentiality.

The same year Barsky and West (2007) published a qualitative study that explored service user's perceptions of recovery and compared it between high and medium secure settings, of which they all had experience. Six male patients with a history of paranoid schizophrenia or personality disorder diagnosis (no type specified), and who had committed a serious violent offence, were interviewed. The transcripts were analysed using thematic content analysis.

Five of the six participants indicated a preference for medium secure settings due to the increased access to ward activities and time outside the unit which they reported improved their quality of life, helped create a sense of hope and progress, and promoted social inclusion. Relationships with other service users and staff were also reported to be more positive. All of these factors were deemed to contribute to the promotion of recovery.

More recently Mezey, Kavuma et al (2010) undertook a qualitative research study looking at the perceptions, experiences and meaning of recovery for forensic, psychiatric patients. Eight men and two women, all with a diagnosis of paranoid schizophrenia or schizoaffective disorder, were interviewed by a service user researcher and a psychiatric trainee who had no direct clinical contact or responsibility for the patient. The interview consisted of two parts: the first was an open ended interview to elicit the meaning of recovery for each individual as well as the factors that helped or hindered the process; the second part asked questions related to domains of recovery identified in previous literature. The transcripts were analysed using thematic analysis and the open coding tools of grounded theory.

The main finding was that the concepts of hope, self acceptance and self management - central to recovery principals - are more problematic for this group of service users and they viewed the consequences of the offending behaviour as the greatest obstacle to recovery.

Medication was seen as very important and participants deferred to staff to assess the extent of their recovery. Feelings of shame, low self esteem and stigma were wide spread, however, many felt that they were afforded more respect, tolerance and understanding in the secure unit than they would be in the outside world. Therefore, although discharge was an important indicator of recovery it had the potential to be de-stabilising and could result in further offending and breakdowns.

The study was, again, limited by the fact that participants knew the interviewers. Furthermore all participants were located in one service so that the findings reflected the aspects of that particular service. The fact that participants were selected for their suitability for interview meant that themes identified were specific to that group and not generalisable across the unit. The enormous variation in accounts made the identification of overarching themes more difficult and the small number of female participants precluded the consideration of gender issues.

These studies highlighted a number of issues specific to people placed in secure units including the compounding factor of having a criminal record as well as a mental illness, the lack of opportunities to assume personal responsibility and the ambivalence about leaving the ‘safety’ of a secure setting. However these studies comprised mainly male participants with diagnosis of psychotic illness rather than personality disorder. The concluding section will consider the challenge of bringing together the principals of personal recovery with women diagnosed with BPD in a secure setting.

Recovery, women and secure care

In ‘the see-saw of recovery in women in secure care’, Birch (2011) described a secure service designed to care for and promote recovery in women who had been given a diagnosis of personality disorder, had a long history of using mental health services and a history of

aggression to themselves and others. Using an attachment framework, the unit prioritised the development of meaningful relationship between service users and staff (Long, Fulton & Hollis, 2003) and recorded some successes in reducing levels of self harm and moving some women on into community placements.

The service model was based on the theory was that through developing relational security with staff and other service users the women would be empowered to choose new ways of expressing distress and would resort less frequently to self harm or aggression. However the challenge was how to foster responsibility and choice in women who were restricted emotionally and cognitively as well as legally and physically (Roberts, Dorkins, Woolridge, & Hewis, 2003).

Reder and Duncan (2001) described a 'care conflict' in which actual experiences of childhood abuse and neglect engendered a fear of being abandoned which created dependency on services. For women with personality disorder diagnoses, recovery may be seen as code for services being withdrawn - problematic for women for whom services are equated with safety. Birch observed that, setting expectations beyond the women's current capacity could lead to them failing to live up to them and feeling like a failure – undermining recovery.

Birch argued that an important step for the women was the realisation that distress could be expressed and support elicited in a number of ways without resorting to self harm. She advocated a piecemeal approach to recovery in which each piece is viewed as an opportunity to replace negative power (self harming) with the positive power of self determination. She highlights that, as many of the women in the service did not have the opportunity to develop secure attachments in childhood, they needed sufficient time for reparative experiences in services before they can contemplate independence. Therefore separation from mental health

services should happen in a very gradual manner. Birch concluded that, although the service recognised the women's need for support and nurturing, it had not recognised how long this would be needed for.

Discussion

Over the last ten years it has been acknowledged that the specific mental health needs of women in secure units have not been given sufficient consideration. This review has highlighted that women's mental health difficulties tend to be exacerbated by factors based in their social context, including relationships, poverty and unemployment. Women are also more frequently than men, are victims of abuse and violence, which can be devastating for mental health. Social networks are one of the main protective factors for women's mental health and when these are damaged some women have few other resources to draw on and turn to mental health services.

In secure mental health units, in which women are a small minority, the difference in the social and offending profiles are even more greatly pronounced. These women are more likely to have been Looked after Children, experienced sexual abuse, use self harm as a coping strategy and have been given a diagnosis of BPD.

BPD is one of the most stigmatising mental health disorders and ,historically, diagnosed individuals have been labelled as manipulative and untreatable. However over the last decade retrospective and prospective studies indicate a more positive prognosis for diagnosed individuals and effective treatments, such as MBT and DBT have been developed. These studies have focused primarily on the alleviation of symptoms, such as self harming and hospital admissions and occasionally, on the improvement in social functioning.

However in mental health services in this country there has been an increasing emphasis on personal recovery which is defined by the service user themselves, is viewed as a journey with progress and setbacks, without a defined end point, and may focus on coping better with mental health difficulties, rather than the elimination of symptoms. In one model, developed from service user narratives, the tasks of recovery are identified as developing an identity beyond mental illness, assuming responsibility through self management, meaningful understanding of the illness and, the development of new social roles.

There has been a move to apply recovery principals in secure setting, seen by many as antithetical to recovery due to the limited opportunities for self determination, choice and meaningful occupation, and the tension between recovery principals and public protection. Nevertheless a proposed model for secure recovery suggested four components: the creation of a therapeutic environment; access to meaningful occupation; access to therapy; and relational security.

To date only three published papers have addressed secure recovery from the perspective of the service users. Relationships with staff and family, access to meaningful activities, medication were identified as factors that promote or undermine recovery. However the vast majority of interviewees were men diagnosed with schizophrenia, furthermore each study was conducted at one site by researchers known to the individual.

The only literature to consider recovery in women diagnosed with BPD in secure settings described how one service drew on theories of attachment to improve relational security for the women patients with the aim of reducing the need for DSH and aggression. The women's fears of being abandoned, the length of time support was required for, and the question of who decides when individuals are ready to move on were identified as issues, specific to this group, that may impact on recovery.

Further Research

This review highlights the significant gap in the literature with respect to personal accounts of recovery for men and women diagnosed with personality disorder. For reasons discussed above, recovery approaches developed specifically with the field of schizophrenia may require some modification for use with people diagnosed with personality disorder, what these may be, may be explored by speaking to the individual's themselves.

There is also no published research on how women in secure units understand and experience their own recovery, including those with a personality disorder diagnosis. One might predict that given the differences between the offending and social profile of men and women in secure services, their recovery needs and objectives may be different. One way to establish whether this is the case would be to design a qualitative study comparing the accounts of recovery from both men and women diagnosed with PD in secure settings.

However, in order to develop an understanding of personal recovery as it relates to this group of women qualitative research is needed that addresses the following question:

- How do women with a diagnosis of personality disorder in secure settings define and understand their own recovery?
- Which factors serve to support or undermine recovery?
- What impact has the diagnosis of personality disorder had on the recovery process?
- How do recovery principles interact with the constraints of a secure setting?

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Section B

Abstract

Objective: To explore the concept of recovery in women diagnosed with personality disorder in a secure unit.

Method: Six semi- structured interviews, conducted with women diagnosed with personality disorder and experience of being detained in secure accommodation, were analysed using Interpretative Phenomenological Analysis.

Results: Analysis of the transcripts revealed five master themes: recovering; centrality of relationships; assuming responsibility for own care; evolving an identity; understanding of the mental health experience.

Conclusion: As far as is consistent with a secure setting, women should be given maximum opportunity to participate in decisions about their own care. Staff should be creative in providing opportunities for the women to engage in meaningful activities that promote a

positive identity. Education with respect to personal recovery and the presentation and aetiology of personality disorder may support more caring and hopeful relationships between staff and service users, within which recovery can be facilitated.

Introduction

Over the last decade it has been acknowledged that women in secure settings often find themselves marginalised in a system primarily designed for men (DoH, 2002). The social and offending profiles are markedly different between men and women and the implementation of gender specific care pathways has been recommended. Many of the women in this system will attract a diagnosis of personality disorder (PD), most commonly, borderline personality disorder (BPD), which will have implications for the type of care they need.

Recovery based approaches are now being applied to work with this client group as there is a trend to move from clinically based definitions of recovery, with a focus on remission of symptoms, to more personal, self defined, understandings of recovery such as that described by William Anthony (1993):

A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful and contributing life even within the limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness. (p.13)

The use of recovery based approaches for this group of women is challenging, firstly, with respect to the secure setting which can act contrary to recovery principles of self determination and access to meaningful occupation. Secondly, women who have received personality disorder diagnoses often find interpersonal relationships - the bedrock of recovery - particularly challenging.

Women, mental health and secure settings

Compared to men, women in secure settings were more likely to have been transferred from the NHS under the civil section of the mental health act, have a history of arson not violence, have a history of abuse and self harm, have physical health problems and been diagnosed with BPD (Home Office, 1999). A study exploring the differences between men and women detained in secure hospitals recommended that women needed to be understood within a social context of gender inequality and called for assessment to consider the social and economic contributors to mental distress (Stafford, 1999).

Borderline Personality Disorder and recovery

The key features of BPD are instability of interpersonal relationships, self image and affect combined with marked impulsivity (APA, 1994). Diagnosed individuals report being labelled as manipulative, attention seeking, difficult and untreatable (Haigh, 2002).

Karaklic & Bungener, (2010) conducted a literature review of outcome studies that showed the prognosis for people diagnosed with BPD had become more optimistic. In the most recent study, Zanarini, Frankenburg, Reich, & Fitzmaurice (2010) examined the time to attainment of recovery from BPD and its subsequent stability in a 10 year prospective follow-up study. Full recovery was defined as a Global Assessment Functioning (Endicott, Spitzer, Fleiss &

Cohen, 1976) score above 61 (mild symptoms), at least one emotionally sustaining relationship, and the ability work full time.

Fifty percent of participants achieved full recovery, whilst ninety percent experienced a remission of clinical symptoms, suggesting that good social and vocational functioning is harder to achieve than reduction of symptoms. The authors recommended that treatment refocus on promoting good psycho-social functioning.

Secure Recovery

There is limited evidence regarding the applicability and value of a personal recovery approach in secure settings (Turton et al. 2009). Merzey, Kavuma, Turton, Demetriou, & Wright (2010) asserted that legal detention compromised the capacity to exert choice and control over treatment and long periods of time spent in secure settings could undermine hope and optimism, and the promotion of self care and independence.

Alred and Drennan (2007) described the challenge of integrating recovery with a duty of public protection and proposed that the development of a therapeutic environment, access to meaningful occupation, access to therapy, and relational security were all necessary to promote recovery.

Qualitative research into secure recovery

To date, only three published studies have explored how individuals with severe mental health problems, detained in secure units, define and understand their own recovery.

Lathwaite and Gumley (2007) interviewed twelve men and one woman with a diagnosis of schizophrenia on a high secure unit. All participants spoke of the importance of relationships with family and staff. Themes of fear versus safety, feeling entrapped, coping, meaningful outcomes and the development of trust emerged in relation to the secure setting.

Barsky and West (2007) compared individual experiences of recovery between high and medium secure settings and found that increased access to ward activities, time outside the unit, and more positive relationships with staff and other service users, served to create hope and promoted social inclusion.

Most recently Mezey et al. (2010) explored meaning of recovery for forensic psychiatric patients and found that the concepts of hope, self acceptance and self management, central to recovery principals, were problematic for this client group. Many felt that they were afforded more respect, tolerance and understanding in the secure unit than they would be in the outside world.

Recovery, women and secure care

In the only paper to specifically consider recovery in women who had been given a diagnosis of personality disorder and were placed in a secure unit, Birch (2011) described a service which used an attachment framework to prioritise the development of meaningful relationships between service users and staff (Long, Fulton & Hollin, 2008) in the hope that women would be empowered to choose new ways of expressing distress without resort to self harm or aggression.

The challenge was that, for women with actual experiences of abuse and neglect, recovery may be equated with services being withdrawn and a re-experiencing of abandonment, that potentially affected their motivation to 'get better'. Birch (2011) highlighted that the women needed sufficient time for reparative experiences before they could contemplate independence. She recommended a graded, gradual separation from mental health services.

Further Research

The introduction has highlighted the specific challenge of recovery faced by women, diagnosed with personality disorder, and placed in a secure unit. It has been suggested that women in this situation require a different care approach to men which takes account of gender specific issues, such as the aetiology of mental distress and offending behaviour.

All the current personal recovery based approaches have been developed in the field of schizophrenia (Bonney & Stickley, 2000). However, given that recovery is essentially a social process (Schon, Denhov, & Topor, 2009) and individuals with diagnosis of personality disorder often experience significant difficulties in interpersonal relationships one might predict that this could raise some complex issues as suggested by Birch (2011).

Models of personal recovery are grounded in service user accounts of their experience. However there are no published accounts of how either men or women, with a PD diagnosis, define and understand their own recovery. Although there have been a number of longitudinal studies examining outcomes in people with diagnosis of PD, these have focused on clinical recovery, as evidenced by reduced self harm or number of admission to hospital.

With respect to secure recovery, the three published qualitative studies were conducted primarily with men diagnosed with schizophrenia or schizo-affective disorder. There is a significant gap in the literature with respect to personal accounts of recovery for both genders with a personality disorder diagnosis, as well as for women in secure settings.

The present study

In order to develop principals for personal recovery amongst this group of women it is important to speak to the women themselves. The main aim of this study was to explore recovery in women with a diagnosis of personality disorder in a secure setting. This was

achieved by conducting individual semi-structured interviews based around the following questions:

- How do the women understand and define their own recovery?
- What factors support and/or undermine recovery?
- What impact has the diagnosis of personality disorder had on the recovery process?
- How do recovery principles interact with the constraints of a secure setting?

Method

Participants

Participants were recruited from two NHS and one private medium secure unit. Potential participants were identified by the clinical psychologist or psychiatrist working in the service and a designated clinical psychology assistant supported the researcher in approaching the women and obtaining consent. In total thirteen women were interviewed.

The inclusion criteria were that the participants be female, aged 18 years or older, be currently or have previously been resident in a medium secure unit within the last 2 years, to have been diagnosed as meeting the DSM-IV criteria for a personality disorder at some stage in their mental health history, be able to give informed consent to participate in the study, and have been assessed by the MDT as being sufficiently psychologically robust to participate in the interview.

All the participants were of white British origin and aged between 19 to 34 years. Twelve of the women had a diagnosis of borderline personality disorder and one had a diagnosis of anti-social personality disorder. Eleven of the women were currently resident in a medium secure unit, one was in an open unit and one was living in the community.

None of the women had a partner and although eleven of the women had contact with a range of family members it was hard to establish to what extent these were supportive. There was a range of educational achievement amongst the women - one was an academic, another was a qualified health professional, several women had obtained GCSE's and A' levels, whilst a number of women had entered secure mental health services prior to finishing school. Seven of the women were placed in medium secure settings due to having committed criminal offences, whilst the remaining six has been placed there due to the severity of their self harm.

Undertaking qualitative work with this client group proved to be unpredictable. Two participants terminated the interview after 10 minutes, another two presented as heavily sedated and were unable to remain awake, and another three did not given sufficiently detailed or reflective responses to allow for analysis. The reasons for this were not clear, however, this was also found to be the case in the study conducted by Laithwaite and Gumley (2007). For these reasons only six transcripts were included in the analysis which remained within the number of participants recommended for IPA (Smith, Flowers, & Larkin, 2009).

Of the six transcripts included in the analysis only two were by women who had committed an offence, one of these women ended the interview before the impact of this could be discussed. This meant that the impact of offending on the recovery process was not identified as an over-arching theme and was not included in the analysis.

Measures

A semi structured interview was utilised to explore the women's understanding of recovery with respect to their mental health difficulties within a secure setting. The interview schedule was developed in conjunction with the clinical supervisor (Appendix 2). A service user consultation provided feedback on the language and content of the schedule, the information sheet (Appendix 3) and the consent form (Appendix 4). A pilot interview was conducted with one participant who confirmed that the questions were clear and relevant.

Ethics

The study received NHS ethical approval and Research and Development approval from the trusts prior to contact being made with participants (Appendix 5). Written consent was obtained from all participants prior to interview. Participants were informed that they could stop the interview at any time without giving a reason and given access to their key worker for support if necessary afterwards.

Procedure

Women identified as potential participants were approached by the clinical psychologist or psychiatrist in the service to ascertain if they would be interested in participating in the interview. The assistant psychologist/psychiatrist went through the information sheet with the women and gave them a copy of the consent sheet. Nine of the women opted for an initial meeting with the interviewer prior to giving consent, four decided to proceed straight to the interview.

Consent was obtained immediately prior to the interviews which took place in a private room in the secure unit or a community unit. The analysed interviews lasted between 30 minutes and 105 minutes. Participants were given space to reflect and ask questions at the end of the interview and were informed that they could contact the researcher by telephone if they had any further questions. The interviews were digitally recorded, transcribed verbatim, anonymised, and stored on a password protected computer. Digital recordings were destroyed after transcription. Participants were offered the option of meeting to discuss the findings or being sent a summary of findings in the post. Letters were sent to participants' care coordinators informing them of their involvement in the study.

Methodology

The interview data was analysed using Interpretative Phenomenological Analysis (Smith et al. 2009). This approach provides a detailed examination of an individual's lived experience and how they make sense of their personal and social world. There is a two way process of interpretation with the participant trying to make sense of their world and the researcher trying to make sense of the participant's interpretations – drawing on appropriate research and psychological theory.

This methodology is best suited for exploring complex psychological phenomena in small, homogenous participant groups, such as the one utilised in this study. Nehls (2000) advocates this method of exploring recovery in relation to personality disorder as a means of a developing a practical theory of recovery which is grounded in the lived experience of the participants.

The transcript data was according to the IPA stages outlined in the Smith et al. (2009).

1. The transcript was read and re-read and, initial notes and comments of interest were made.
2. Emergent themes were identified.
3. Connections between the themes were noted.
4. A table of master themes and subthemes was compiled.
5. This was repeated for each transcript.
6. Patterns across the cases were identified and a table of master themes for the group was collated.

Quality Assurance

In accordance with recommended practice a clinical psychologist conducted an independent audit on several transcripts to check that the themes were valid in relation to the text being analysed (Turpin et al. 1997). The inclusion of an analysed transcript, (Appendix 6), and a table of transcript excerpts corresponding to the master and sub themes (Appendix 7), provides a transparent audit trail. The results section incorporates verbatim excerpts of participant accounts to illustrate the themes and excerpts from a research diary are included in the appendices to illuminate the context of the interviewer and the research process - including the development of themes (Appendix 8).

Results

The research explored how the women defined recovery for themselves and what they felt supported or undermined their recovery. Whilst the individual accounts varied, five master themes were identified through IPA. Subthemes derived from the master themes are

presented systematically with accompanying extracts from the transcripts – edited to ensure confidentiality.

Master Themes	Sub Themes	Number of participants
1.0. Recovering	1.1. Defining recovery 1.2. Recovery as a journey	All All except P2 and P8
2.0. Centrality of Relationships	2.1. Experiences of care 2.2. Being known and understood 2.3. Communication and fostering trust 2.4. Vehicles for hope and motivation for the future 2.5. Impact of relationships to other women 2.6. Fear of abandonment	All All except P8 All All except P8 All All except P13 and P2
3.0. Assuming responsibility for own care	3.1. Being an active participant 3.2. Being ready – whose decision 3.3. Role of medication 3.4. Taking control and making choices 3.5. Being thwarted	All All All All All except P13
4.0. Evolving an Identity	4.1. Developing a sense of self 4.2. Meaningful occupation 4.3. Caring for others 4.4. Impact of diagnosis	All All except P13 All except P13

		All
5.0. Understanding of the mental health experience	5.1. Seeking self understanding	All except P8
	5.2. Understanding self harm	All except 10 &13

1.0. Understanding Recovery

1.1. Defining Recovery

The research indicated that all the participants had a view on the aim of recovery but that this varied from more clinical objectives, such as:

Recovery means not self harming, not getting distressed or being restrained or stuff like that and being settled. (P2)

To explanations that framed recovery as a process:

Recovery is like learning to cope better than you usually do... (P8)

Recovery ... getting better, moving on, going home ... (P9)

1.2. Recovery as Journey

P9 and P11 used metaphors to illustrate their sense of being on a journey, marked by progress and setbacks and without a specified end. The experience of overcoming difficulties appeared to give them hope and determination to persevere:

Yeh it's like it is a journey and you can be in that dark hole and you can recover you can get out of that dark hole and recover and move on (P9)

It's like a ladder and you've got to climb it and sometimes you'll get to the fifth step and you'll go back a couple but you'll get there ...there was many ups and downs that ladder. (P11)

2.0. The centrality of relationships

For individuals diagnosed with a personality disorder, relationships with others can be complex and fraught with difficulties. However the research highlighted how the development of nurturing and sustaining relationships was essential to the recovery process. Conversely poor relationship served to impede communication and undermined trust and the belief that progress was possible.

2.1. Experience of care

All participants described the power of experiencing authentic care from staff which provided a potentially reparative experience in which the participants could start to view themselves as deserving of care:

Just in the way you're treated differently like that, it made you feel that actually they do care about how I feel. (P11)

It's quite funny it makes me laugh at myself cos when they go 'no you're not ready' it makes me feel protected and looked after. (P13)

The research suggested that a lack of care mirrored early experiences of neglect and reinforced low self-esteem and sense of hopelessness which worked against recovery:

*You could walk past a nurse or something and they *wouldn't even remember your* name or they would call you something else – like Sarah or something - that happened a lot and in the end I just answered to whatever they called me. (P11)*

2.2. Being known and understood

All, bar one of the participants, referred to the importance of being known and understood by others. Individuals diagnosed with personality disorder may experience persistent instability

in their sense of self therefore the knowledge that they are knowable and understandable can provide reassurance as well as the possibility of acceptance:

I've worked with her for years and she ...my mum says ...you always knows what's going on in my head my psychologist is similar ...I can't lie to her or if I do she looks at me as if to say ...in a way it's a bit annoying cos I don't want her to know but in a way its good cos she knows me well...she knows a lot about my past she knows huge amounts about me. (P11)

2.3. Holding the hope and motivation to be different

The research revealed that although relationships could be challenging, by allowing themselves to invest in relationships, some women found the motivation to try different ways of behaving:

It became very difficult after a while to lie to them (staff) ... and after a while I started to feel that not only was I letting myself down I was letting staff down as well, who were doing their best to help me and there was me going behind their backs and lying to them and after a while I started to feel quite bad about that. (P11)

Through significant relationships, hope could be maintained when the participant was struggling to belief in themselves:

I said to my psychologist 'I've given up I want to die I can't cope no more with my life' and my psychologist said remember you were in this dark hole before and you pulled yourself out ...I said I can't do it no more I was too depressed I was too emotional I'm just going to stay in this hole and she said 'you're not you will get out of there'. (P9, Line 370)

2.4. Communication and fostering trust

The research highlighted the importance of honest communication as a vehicle to develop trust. It was only within the context of a trusting relationship that participants felt safe enough to start addressing their difficulties:

I trust the staff here now and it's very hard for me to trust, very hard, it took me two years of psychology to open up and they didn't just abandon me they kept going.

(P13)

Several of the women described how poor communication excluded them from participating in their own care:

I tried asking my psychiatrist (about diagnosis) but I didn't get anything that made any sense he just talked in doctors talk and I used to be like ...there's no point talking to you cos I don't understand a word you're saying. (P11)

2.5. Relating to other women

Relationships with other women on the ward were particularly significant and reference was made to the potential for support and the validation of a shared experience:

when I've really needed to be comforted it's been one of the girls who's come up and put her arm around me and just held me ... it's so powerful ...someone who understands why you're upset and just feels for you. (P10)

However the majority of participants highlighted how difficult it was to manage the distress of the other women on the ward and described how they acted to protect themselves at times:

It was chaos, people were self harming all over the place ...nightmare and I ended up drinking ...that was my way of coping and crying out for help. I remember lying in

my room thinking I'm either going to tie something round my neck or drink and I went for the drinking. (P13)

Some of the patients struggle a bit sometimes and you try and support them but I try *not to get too involved as you've got your own issues to deal. (P2)*

2.6. Fear of abandonment

The majority of the participants mentioned actual experiences of disrupted attachments which caused them to fear being abandoned again by services:

It's like how can I trust you when you are going to bugger off anyway cos being in care you get moved around a hell of a lot and when I was younger I never quite stayed in one place so I was back and forth everywhere ... so I don't trust people cos I just think you're just going to get rid of me again ... (P8)

The fear of losing support meant that the prospect of 'getting better' became a frightening concept for some women. A number of the participants described worrying that all support would be withdrawn if they showed any sign of progress:

I'm scared of my good days ... I get scared of them cos I think you're going to try and chuck me out before I'm ready cos I don't just have one good day and that's it, it will be like I have a good day and then suddenly I have one of the worst days ever. (P8)

3.0. Assuming responsibility for own care

This theme highlights the sense of empowerment derived from being an active participant in one's own life and reassuming control over decisions, such as taking medication and deciding when the time is right to move forward. Taking back control from the professional network and working in partnership is a key task of recovery.

3.1. Being an active participant

All participants described how important it was for them to be more involved in their own care in order to develop a sense of agency and competence:

I've always taken responsibility and that's very important for me and I find that very empowering and for taking responsibility for myself I am owning my life I take it back and I can do things with it and I can make it better and I think that's crucial for recovery. (P10)

The consequences of not being supported to take responsibility, was almost catastrophic for Participant 11:

before I went into XXX everything was taken off you and I actually caused myself more harm ...I mean they took everything off me and I did some ...the worse thing ...I set myself on fire... I think that maybe if I'd had more responsibility I wouldn't have done such an extreme thing. (P11)

3.2. Taking control and making choices

Related to the sub-theme of being an active participant is the ability to take control and make choices which research suggests is tremendously important for the process of recovery.

Participant 11 gave a powerful account of how, despite the risks, having control over whether she lived or died changed her life:

I had cut my throat seriously ... it must have been a split second but I sat there and I actually had a choice ...do I just lie here and bleed out and die or do I knock on the door and try and get some attention and some help. And urr I think that's the only time in my life where I've been in that situation and where I genuinely 100% have been in total control over life and death and whatever reason although you really

want to be dead ... you don't ...deep down you really don't and although it was obviously there was huge risk it was ... my turning point (P11)

Having the freedom to make choices enabled participants to make positive choices for themselves underscoring that they were able, in some circumstances, able to judge what was best for them, enhancing their sense of self efficacy:

I actually learnt to choose the better the option ...I had to learn to choose um talking rather than self harming (P13)

3.3. Being ready to move forward – who decides?

Integral to the concept of recovery has been the idea of moving forward. The question of who makes this decision and what constitutes progress can be complex. The research identified a tension between the participant not feeling ready, possibly connected to a fear of having support withdrawn too quickly:

They think I can just get on with life and be what everyone classes as socially acceptably normal ... and not to out of it, but I find it really hard ... the minute that someone puts pressure on me I cave under again ... (P8)

Contrasted with some participant's experience of feeling they were being held back by professionals and the restrictions of secure settings, undermining any sense of autonomy:

I waited a year and half to do the trauma work I kept moaning at my psychologist *about doing the trauma work and ... my psychologist kept saying you're not ready*

you're not ready you're too emotional you're too down you're too stressed and now I'm ready and I've started it and I'm fine (P9, Line 94)

3.4. Role of medication

All of the participants were on large quantities of medication and the research identified a high degree of ambivalence about their role in treatment. A number of participants expressed dissatisfaction with medication and questioned its appropriateness for treating PD:

As soon as you get admitted you're handed a couple of blue pills and you're like 'what's this then' and they're like 'oh nothing just two tiny little pills' and two minutes later you're zonked out you know on larazopam... you're given these addictive medications and it takes a long time to come off them (P11)

I really don't believe in medication for treating PD as I don't think it goes any way to addressing what's wrong (P13)

However some participants felt that medication was essential for their well being. However, the accounts suggested that, in some cases, the perceived benefits of medication may serve to undermine the participant's sense of being responsible for their own progress:

Dr XXX and my psychologist keep saying 'I can't believe how much you've changed ...before I was on Clozerole I was in and out of seclusion, I was in extra care, I would chuck chairs and since I was on clozerole I've had no incidents ...it's a really good drug I would never stop taking it because cos its just done a world of good for me it's really helped (P9)

3.5. Being thwarted

The research revealed many experiences of participants being denied the opportunity to assume responsibility for themselves, including restraint, being treated like a child, and ‘playing the game’. The practices of restraint and seclusion were described as assaults that served to exacerbate emotional difficulties:

They either say you come the easy way or the hard way ...if you refuse to go to seclusion they'll literally drag you all the way to seclusion ... it's not nice it's not a very nice place at all ...(P9)

Feeling that one was ‘playing the game’ hindered honest communication and genuine progress:

You had to give reasons why you wanted to go out to the garden ...and I'd be like 'cos I bloody well want some fresh air' and they'd be like 'no its got to be more than that' you'd have to explore why – you want to feel the wind in your hair ...you want to hear the birds. (P11)

The loss of self determination positioned some participants in the role of a child rather than an adult with the capacity for self determination:

Sometimes in here, the way they treat you and stuff is quite like patronising calling us girls - I hate it cos we're not girls – and you hear about bad behaviour and good behaviour I don't think those are terms they should use –I was treated like a child as an adult and I don't want to be treated like a child that really bugs me (P2)

The sense of being punished was a recurring theme throughout the research, exacerbated by the prison-like regime in some of the units:

They don't treat you as patients ...unwell, they kind of treat you like you're in prison like with all the doors locked ... you've got to build your leave up and they always

lock the doors and the food...it's all like, I mean, they don't look at you like you've got problems ...to me it's like they punish you for being unwell. (P9)

4.0. Evolving an Identity

Mental illness can lead to the loss of a sense of self or an identity that is located solely within the context of mental health problems. This research suggests that the formation of a positive or 'normal' identity beyond mental illness is an essential part of the recovery process. This involves moving from a negative to more positive sense of self and is influenced by access to meaningful occupation and a valued social role. All participants identified the stigma associated with a personality disorder diagnosis as an obstacle in this process.

4.1. Developing a sense of self

A number of participants provided negative descriptions of self - experiencing themselves as scary, invisible and undeserving of happiness:

It's quite scary to be yourself ...I feel like I'm six years old and all I want to do is stamp my feet and cry (P8)

You were able to learn to become someone and not just a number ...for so many years it felt like I wasn't a human being (P11)

Sometimes I'd punish myself cos I had a good day cos I felt like I was bad I'm not entitled to have a good day (P11)

However the research revealed that there was some shift in self perception amongst some participants towards a more positive, more 'normal' sense of self:

You know it's not my whole - like I'm not XXXX the self harmer and personality disorder (P11).

I went to big Tesco's it was just like normal – normal people go there and um so it felt good (P2)

4.2. Meaningful occupation

The research highlighted the importance of access to meaningful occupation as a way of facilitating the development of a positive identity. All, bar one, participant explained its importance for feeling part of society, making a contribution, and helping them maintain good mental health:

I think if I could get up on a Monday morning and be like most people ... I think that gives you more meaning to life and also makes you part of society again cos I'm paying my way and if I'm paying my way in life I have a right to complain whereas now I feel like I don't have that right. (P11)

I think it's important because you just ruminate if you're home not working ... you just ruminate over things and it can bring you down again so the best things to do is to try and keep busy and stuff ... a job is important in your life as it gives you a bit of self worth and stuff so I think it's important. (P2)

4.3. Looking after others

With the exception of one participant, all expressed a wish to be involved in the care of others, particularly those who may be deemed vulnerable, including animals, older people, children and other mental health service users. It's possible this may reflect a wish to provide the care and protection that they had not been afforded or to have something that provides unconditional love, in the case of a pet:

I am quite keen on going back to university and becoming a social worker for children. (P2)

it's a life (having a pet) that relies on me to look after it and keep it alive and well it means I've got like a meaning to live ... Something needs me so I've got to be there for it. (P8)

Several participants described how they could draw on their own experience to help educate others about personality disorder or self harming, thereby transforming their own difficulties into a force for good for others:

there was a speaker there who is an ex service user and he is involved in a consultation for the mental health service in various different places and I would love to work in that kind of capacity ...working to make it more effective ... so that more people get what they need (P10)

A lot of people come up to me afterwards and shake my hand (after giving a talk) ... I can go home and think 'OK I've done something worthwhile today ...I've helped someone out...if I've said one word that makes one difference then it's all worthwhile (P11).

4.4. Impact of diagnosis

This research highlighted the stigma associated with the diagnosis and its capacity to reinforce a negative sense of self and reduce hope for a better future – both of which undermine the process of recovery:

I didn't like the label at all because I think it's got a bad reputation there's a lot of people who think ah she's got a personality disorder – there's nothing wrong with

her and stuff like that and when I found out the diagnosis it's not very nice as you get a lot of negative views on it. (P2)

I knew that it was a red flag to mental health services ... I knew people were going to view me as a difficult case, with PD it will be difficult to treat her, she's untreatable ...she's not ill she's making it all up she's trying to get attention. (P13)

The reductionist aspect of the diagnostic process was also emphasised as the complexities of participants' lives were reduced to a check box exercise or the completion of a questionnaire:

I saw the psychologist and I thought I don't like you and I'm not going to get on with you I'm not sick I haven't got all that and she was like ...well did you fill out this questionnaire and I filled it out and they just came up with diagnosis for me. (P9)

5.0. Developing an understanding of the mental health experience

The research demonstrates how participants needed to make sense of their experiences in order to move on with their lives, for some participants this process was facilitated by their diagnosis which provided a framework within which to understand their experiences.

Reconciling difficult events from their past was integral to this process and helped create a narrative that allowed for greater self compassion and understanding from others.

5.1. Seeking understanding of the self

The research indicated the importance of a constructive therapeutic relationship to supporting the participant in better understanding themselves and their behaviours:

she explained why – for example – I have this really bad fear that before I get out of hospital that something really bad is going to happen to my mum and that she would be involved in a car accident or something horrible like that and she explained that

it is normal for me because I was ... I wasn't rejected by my mum ... but my mum put her partner first so I was rejected as a child. So now I am worried that it will happen again. (P2)

Although the drawbacks of diagnosis were recognised by many of the participants, the value of having a framework within which to organise and explain previously incomprehensible experiences was viewed as extremely helpful by some:

not that I want ... to be labelled as anything ...but I think it then became easier to explain to my family and you know people outside of mental health why I was like, I was that it wasn't my fault but I think more for myself cos then I could work on that rather than 'Oh my god I'm going mad I'm going crazy'. (P11)

5.2. Understanding self harm

The research indicated that lack of understanding about the function of self harm and the associated negative reactions, and lack of care hindered the recovery process. The participant's themselves demonstrated a compassionate understanding of the phenomenon as a communication of distress or a coping mechanism. A lack of understanding amongst mental health professionals had serious consequences for one participant:

A big one for me is self harm and the reasons people do it and the difference between suicide and self harm you know how there is such huge differences ...but people still don't see it ...I have had it where I've been sectioned because I've self harmed they've been like 'you've cut yourself you wanted to die didn't you and I'm like 'No I cut my arm it didn't mean I wanted to die. (P11)

Its attention seeking and stuff and my CPN in the community said we all crave attention for some reason it's not a bad thing. It's something like they're upset and distressed and trying to receive help so I don't like it when other patients say nasty things about them. If they're attention seeking then it's for some reason it's not a detriment thing – they're just saying they need help and stuff. (P2)

Discussion

This research project provides a new, qualitative perspective on how women in secure settings with a diagnosis of personality disorder define and understand their own recovery. This group of women faced considerable obstacles to their recovery. The mental health difficulties that led to their diagnosis, including fear of abandonment, unstable and intense interpersonal relationships, and deliberate self harm, made the formation of supportive and enduring relationships particularly difficult. The diagnosis of personality disorder, especially BPD, continues to be extremely stigmatising, with implications for self esteem and self image. Furthermore the secure setting severely limits the options for self determination and meaningful occupation. The fact that all the women believed, to varying degrees, that recovery was an option for them was a testament to their resilience.

Although there were significant variation between the accounts of the six participants, five over arching themes emerged from the analysis: defining recovery; centrality of relationships; assuming responsibility for own care; evolving an identity; and developing an understanding of the mental health experience, all of which interacted with each other. These reflected recovery themes identified in the published literature (Slade, 2010).

All the women offered their own interpretation of recovery although the level of sophistication varied from the abatement of clinical symptoms, such as self harm, to more

complex descriptions of recovery as a journey. This may reflect the differing stages of recovery, variation in cognitive functioning, length of time spent in the service, and the orientation of the service.

The ‘centrality of relationships’ could be viewed as the primary master theme as it was through relationships that they were empowered to resume responsibility, develop a positive identity and come to a meaningful understanding of the mental health experience. Some participants described the sustaining quality of positive relationships within services and with their families, whilst others recalled relationships in which they felt criticised and invalidated. Within each sub-theme, contrasting experiences were described; care versus lack of care; communication and trust versus no communication and suspicion; being known versus not being known; and supportive relationships with other women versus the need to maintain distance to protect oneself from their distress.

The sub-theme of abandonment seemed particularly salient for this group of women. The majority of women had actual experiences of abuse, neglect and disrupted attachments which affected how they related to services. The fear of being abandoned made it difficult for them to form trusting relationships or accept care as genuine. It also made for a difficult relationship with progress as some women were fearful that ‘getting better’ meant they would be ‘kicked out’ of services. Nevertheless some women did form constructive relationships but these developed over a significant period of time.

Assuming responsibility for one’s own care was a recurring theme for all the women. Being involved in decisions about medication and having the responsibility to make choices was viewed as integral to moving forward. However who decided when it was time for the

women to assume more responsibility created tension. Some women felt that they had been pushed beyond their capabilities, which ties into Birch's (2011) assertion that by setting expectations too high risks the women feeling like failures and their recovery being undermined. In contrast to this, the restrictions of the secure setting, coupled with a sense that professionals alone decided when women were 'allowed' to move forward caused frustration and low morale. It was this aspect of recovery that was most different between secure settings and the community - where individuals experienced much greater autonomy.

The secure setting provided a number of examples of practice that served to negate recovery. Several women described the trauma of being restrained, sedated against their will and placed in seclusion, despite having been sectioned because of their mental distress. A number of women explained that these practices were used as leverage in managing their behaviour but served to exacerbate their distress. Being treated like a child, needing to 'play the game' and the belief that they were being punished for being unwell prevented the formation of helpful relationships and precluded the women from taking responsibility.

The remaining themes of evolving an identity and developing an understanding of the mental health experience are closely associated. The development of a meaningful narrative around one's mental health difficulties facilitates a more compassionate view of the self as well as a recognition of one's strengths - which contributes to a positive identity.

Having access to meaningful occupation on leaving secure care seemed to be essential for a positive identity which was frequently aligned with the role of caring for others, particularly those who were deemed vulnerable – children, older people, animals and other service users. The significance of this role may be linked to the less threatening nature of these

relationships, the need for the reparative experience of providing care and the wish to be the recipient of unconditional love (in the case of the animals).

The stress of revisiting past traumas in order to gain a better self understanding should not be underestimated. It is likely only to be possible in the context of a trusting and caring relationship which, understandably, may take time to establish, particularly in this group of women. This is one example of the inter-related nature of the themes that emerged from the analysis.

Strengths and Limitations

The methodology used in this research enabled a detailed examination of lived experience, although the small sample size does not allow the results to be generalised across the population. The fact that women were interviewed from three different units, encompassing both the NHS and the private sector, meant that the results were not just reflective of one specific secure unit.

The fact that the women were selected as suitable for interview by clinicians makes it likely that the most articulate and reflective women were interviewed, which may also relate to how well they were able to access resources to support their recovery. Within this group there was further selection as only the transcripts with sufficient detail for analysis were included. This introduced an inevitable bias towards the more high functioning women. Given the interpretative nature of IPA methodology one also needs to be mindful of the bias introduced by the researcher.

The participants included in the study did represent a cross section of socio-economic and educational status, however all the participants were of white British heritage which may limit the relevance of the findings for women from ethnic minority groups. Furthermore, although the reasons for focusing on women in the study were explained in the introduction, without a male comparison group, it is not possible to conclude that the emergent themes were specific to the needs of women.

Clinical Implications

Research indicates that psychology has an important role in educating and promoting understanding of recovery, PD and the role of self harm amongst staff and services users. Helping staff to develop a more empathetic understanding of the aetiology and function of the behaviour of this group would serve to promote compassion and increase experiences of care - communication could be improved and trust could grow.

A particular issue that needs to be considered is the length of time that women may need support and services for. For women who may have experienced years of abuse and/or neglect - meaningful engagement, the strength to address their past and feeling ready to start the process of separating from services, understandably, will take time. If the professional network is helped to understand these issues, rather than pathologising the women as too dependent, more effective partnership working may occur in which women are afforded more control over deciding when they are ready to move forward. This could allay abandonment anxieties that conspire against recovery.

The literature suggests this is a challenging and, sometimes, distressing field to work in (NIMHE, 2003), but by providing support and consultation to staff about how to more

effectively manage the women's distress could help alleviate burnout amongst staff and reduce incidences of restraint and arbitrary sanctions which undermine recovery.

Psychologists could also take the lead in developing activities on the ward that are more meaningful for the women and better prepare them for managing outside of secure services.

Given the constraints of the setting it may be necessary to be creative, the wish to work with animals was a recurring theme - exploring the ways in which this could be safely facilitated may be an effective way of meeting some of the women's needs.

Developing a meaningful understanding of their mental health experiences was an extremely important theme for many of the women and several of them referred to the role of their relationship with their psychologist in this regard. Good practice, in terms of being respectful and honest, maintaining appropriate boundaries and planning endings and breaks, will be especially important with this group for establishing a therapeutic alliance. Psychologists should also be mindful of ways in which they can empower this client group to have a voice in decisions about their own life as well as providing opportunities to assume responsibility.

Future Research

Given the importance of relationships in a secure setting, a qualitative exploration of how staff view recovery may shed light on differences in perspective that undermine a recovery approach. A comparison of male and female views may help to identify gender specific differences in the recovery process.

Conclusion

Despite significant obstacles, women with a diagnosis of PD in a secure setting, have their own understanding of recovery, and believe that this is an option for them. The development of positive relationships, the opportunity to take responsibility for themselves, evolve a more

positive sense of self and achieve a meaningful understanding of the experiences that brought them into mental health services appear to be essential components of recovery. Practice which works contrary to these objectives, negates recovery. Psychologists have a role in promoting a more hopeful and compassionate understanding of this client group, through consultation, training and research. As well as working therapeutically with the women to facilitate self understanding, psychologists need to think about how they can empower individuals to take control of their own journey of recovery.

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Section C

What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

As a relative research novice I drew upon teaching and recommended reading to learn about different qualitative methodologies which enabled me to determine which was most suited to my research aims. The purpose of this exploratory study was to gain an understanding of the complex and dynamic phenomena of recovery in a specific population. For this reason Interpretative Phenomenological Analysis (IPA) was judged to be the most suited to the research objectives.

IPA is concerned with trying to understand lived experience and with how participants themselves make sense of their experiences, and the meanings these hold for them. IPA is phenomenological in that it tries to explore an individual's personal perception of an event as opposed to producing an objective record of the event itself. Access to the participant's world is dependent on the researcher's efforts to make sense of that other personal world through a process of interpretative activity. IPA work is conducted using in-depth interviews which enable the participant to provide a full, rich account and allow the researcher considerable flexibility in probing interesting areas which emerge (Smith, Flowers, & Larkin, 2009).

Nehls (2000) advocated this method of exploring recovery in relation to personality disorder as a means of developing a practical theory of recovery which is grounded in the lived experience of the participants.

Undertaking qualitative research highlighted the importance of being aware of one's own beliefs and values especially for the purpose of analysis. Prior to commencing my psychology training I worked therapeutically with children who had been sexually abused

including a number of adolescent girls who may have gone on to attract a diagnosis of borderline personality disorder in adult services. I was aware of the fact that I wanted to believe that 'recovery' was possible for these women however they chose to define it. I also carried an assumption that the diagnosis of BPD would be experienced as completely unhelpful to the process of recovery, which was challenged by some of the women's stories as they described how the diagnostic framework helped them make sense of their experiences. I have limited experience with inpatient settings, but anticipated that these would be perceived as helpful - with respect to providing some immediate physical containment - and unhelpful in relation to the loss of autonomy and control. The research appeared to support this view to some extent although the women's accounts varied significantly according to which unit they were in.

The process of obtaining ethical approval required that I learned to hold the tension between not being too intrusive and eliciting the richest material possible for analysis. For example, ethics required that no direct questions were asked about the participant's childhood experiences or mental health history. Any information shared on this topic would be at the volition of the participant.

I learned the enormous value of service user input, two of whom read the project materials and provided feedback on language and content which undoubtedly improved communication with the participants. Personally, I developed skills in explaining the process and aims of the research project for a range of audiences - from ethics and research panels to clinicians and participants.

I developed skills at establishing a rapport with participants, frequently characterised as difficult to engage with. My position of being from outside the service seemed to help the women be more open about their experiences. However I had to practice patience and

perseverance in order to obtain interviews with some of the women – in one instance I travelled two hours to meet with one participant to be told she had changed her mind when I arrived.

While the aim of most qualitative research is not to produce definitive generalisable results, I learned the importance of creating an audit trail to demonstrate the validity of the themes identified and used a research diary to illustrate their development. The length of time taken to conduct qualitative research – both in collecting data and analysing it – became apparent and there were moments when the task of trying to make sense of an enormous amount of data seemed insurmountable.

The value of adopting a systematic approach to this process became clear and many hours were spent printing and cutting out themes and organising them into the most coherent set of themes. The fact that the themes were related, and to some extent, dependent on each other meant that the decision as to which sub theme a supporting quote was assigned was a subjective judgement based on the interviewer's assessment of the context in which it was said. For this reason the hours spent personally transcribing the interviews was a valuable investment in the ability to make the best judgment of the meaning of the transcript.

Having read examples of IPA studies conducted by more experienced qualitative researchers I concluded that practice makes for great improvement and that conducting further qualitative research would help consolidate the skills and abilities that I have started to acquire during the course of this study.

If you were to do this project again, what would you do differently and why?

One of the most frustrating aspects of this project was the fact that thirteen interviews were conducted but only six elicited sufficiently detailed accounts that lent themselves to analysis.

There were several reasons for this; the fact that accessing participants had been identified as potentially problematic, meant I was keen to interview anyone who was identified as a possible candidate and agreed to participate; having met most of the women before interviewing I realised that a number of them may not give the most in depth interviews but ethically I felt uncomfortable denying them an opportunity to have a voice about their care; the nature of this client group meant that they could be unpredictable, not just in terms of their attitude towards being interviewed (two participants asked to stop the interview after less than ten minutes) but also in relation to their medication (two participants were sleepy due to their medication and I suggested that we should end the interview).

To some extent I feel that due to the nature of the difficulties faced by the women, these issues would have been unavoidable. In hindsight the clinicians identifying potential participants may not have had enough experience of qualitative research to recognise the degree of reflective capacity required for a good IPA interview and this could have been remedied by a more thorough explanation of the process of IPA. This also applies to the interviewer - had I been more experienced and skilled I may have been more adept at getting more in depth interview material from a number of the women.

Related to this is the fact that I did not have the capacity to transcribe the interviews as I went along which would have helped to improve my interview technique. Timescales and practicalities meant that the interviews were conducted over a period of several weeks and were immensely time consuming due to the distance of the units. When I came to transcribe the interviews at a later stage I identified flaws in my interview technique such as talking too much, especially with the more reticent participants. I also occasionally fell into a more therapeutic mode of summarising and occasionally validating, however, I would contend that in some cases this did help with rapport and led to greater self reflection and sharing of experiences.

Visiting the units and the content of the interviews was emotionally draining. Walking onto one of the units I was confronted by a number of women, some with extensive injuries from self harm and learning difficulties asking me if I would meet with them. I had a preliminary meeting with one woman and agreed to return to interview her at a later date but was later informed that she had died of her self-harm injuries. The content of the women's stories could be extremely harrowing and contained accounts of severe self-harm and acts of violence.

I felt the need to have a break before starting to transcribe and analyse the accounts. In hindsight, given that my clinical supervisor went on leave just prior to my commencing the interviews, I should have made alternative provision for debriefing following the interviews.

Clinically, as a consequence of doing this study, would you do anything differently and why?

The issue of psycho-education and facilitating understanding of the concept of recovery, and the aetiology and presentation of personality disorder amongst staff and service users, emerged as an area in which clinical psychologists could have a meaningful impact. It could serve to promote hope for positive change and highlight the importance of offering choice and opportunities for self determination wherever possible.

A better knowledge of personality disorder would help service users and staff develop a more compassionate understanding of the associated difficulties, particularly the role of self harm as coping strategy or a communication of distress. This could contribute to the construction of more authentically caring relationships in which service users could safely address their difficulties. Awareness of the long history of trauma that many of the women have

experienced may help to promote patience and recognition of the tension, for some women, between moving on and the fear of being abandoned.

Although it was clear that most of the women interviewed felt that the personality disorder diagnosis was highly stigmatising, if used properly it could serve to enhance self understanding, particularly when it helped to contextualise their difficulties. However the research confirmed my view that diagnosis should primarily be for the benefit of the client and that psychologists should be more active in resisting diagnoses that are deterministic and limit options for the service user. The experience of one service user - who had been in and out of secure units for ten years and had made a number of serious attempts to take her own life, including setting herself on fire and was now living in the community and giving lectures about self harm to nurses - was a salient reminder to never give up hope for a client.

For this group of women the formation of trusting relationships within which therapeutic work can be effective is challenging. Being honest about the limitations of recovery based work in secure units is essential, but should go hand in hand with a commitment to identifying creative ways for service users to work in partnership, make choices, and become involved in meaningful activities that prepare them for moving on. Really listening to what the women feel is within their capacity to achieve is essential to avoid evoking feelings of failure as identified by Birch (2011).

Although the aim of the study was to identify over arching themes across the group, I was struck by the fact that most women had a specific issue that was salient to them – for one it was about better understanding of why they had come to receive a diagnosis of personality disorder, for another it was about having her abilities and strengths validated in some way – careful assessment that seeks to identify these and address these idiosyncratic concerns is

likely to promote the therapeutic alliance and have the greatest impact on the women's recovery.

A final note is related to the value of recording sessions. I found that listening to recordings not only helped me identify ways in which I could improve my practice but also enabled me to better identify recurring themes that seemed most important for individual women.

If you were to undertake further research in this area, what would the research project seek to answer and how would you go about it?

As mentioned above, I found the process of identifying overarching themes reductionist at times. Although every effort was made to encompass the most interesting points, inevitably some aspects of individual experience were lost in the process. Undertaking a single case analysis would have afforded the opportunity for a powerful, in depth exploration of particular person's experience and enabled connections to be made within the person's account. Smith (2009) makes the point that in IPA, quality is more important than quantity when it comes to interviews.

This research project was designed to explore the recovery of women diagnosed with personality disorder within the secure system, primarily because there is currently no published literature in this area, but also because the differences in the social and offending profiles of men and women suggest that there may also be differences in their care and recovery needs. Historically women have been placed in secure settings designed for the male service users. A qualitative IPA project which compares the recovery needs of men with women, both groups diagnosed with personality disorder and in secure units, would help to highlight the extent to which they are different and the same and could be used to further improve practice with both groups.

Finally, given the extent to which recovery appears to be predicated on relationships - especially between staff and service users - a qualitative study exploring staff perspectives on recovery and their beliefs about this group of women may highlight how more supportive relationships can be developed.

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Section D

Appendix: List of themes

1. Care vs lack of care.

just in the way you're treated differently like that it made you feel that actually they do care about how I feel you know not just how the staff feel (P11, Line 94)

you know a proper care team where you know who's on your care team which I hadn't been used to as before when I was in the private clinic if there'd been a nurse and I wanted to talk to them they'd be like 'I can't cos I'm not on your care team' and I'd be like 'but I need to speak to somebody' you know there was like a big brick wall between us whereas although I had a care team at XXX I could talk to any of them it didn't matter ... but the way they worked like it wasn't just a job to them but that they really cared (P11, Line 179)

(Following being restrained) they explained afterwards ...they took me to my bedroom and the nurse in charge came in and actually checked my arms that they were no bruises and I was like 'it doesn't matter, it doesn't matter' and she was like

'No I need to check that we haven't actually hurt you.' And once I'd calmed down they actually explained why they did what they did (P11, Line 534)

I don't know if it was because of the settings...the whole kind of turn around ...the ratio of patients coming in ...they're not there that longI don't know ...that's the difference between them both I felt that I wasn't cared about ...I was just a patient I don't know if it's just staff time or 'it's just going to take too long to explain it to that person'. (P11, Line 629). *Lack of care*

In the end they'd have peop (le who weren't DBT trained at all trying to teach us and you'd be like 'you haven't got a clue what you're reading have you ...and they'd be like 'well not really but there's no-one else to do it (P11, Line 1129)

you could walk past a nurse or something and they wouldn't even remember your name or they would call you something else – like Sarah or something 'no but my name's XXX' – 'OK Sarah' 'No my name's XXX if you can't get that right then how the hell can you possibly do anything else.' - that happened a lot and in the end I just answered to whatever they called me (P11, Line 1150) *Lack of care*

2. Being known and understood

but they were like why can't you get better ...what are you doing ...she's hurt herself again ...how could you let her do that ... um so it took them a while to kind of ...and they were involved a lot with my care through the staff ...if I allowed it I had to give permission um but it all ...to try and give them more understanding of why I was like I was ...like they said, as difficult as it must have been for my family, they can't just click their fingers and make me better yes ...you know ...so they got to understand that 'oh she's cut herself ' it doesn't mean that its disaster and everything's gone caput ...its just part of the process ...of moving forward really (P11, Line 270) *family understanding*

I've worked with her for years and she ...my mum says ...you always knows what's going on in my head my psychologist is similar ...I can't lie to her or if I do she looks at me as if to say ...in a way it's a bit annoying cos I don't want her to know but in a way its good cos she knows me well...she knows a lot about my past she knows huge amounts about me (P11, Line 380)

me and this nurse kept up the competition throughout my whole stay there ... she would pick it up when I was looking ...she would be like 'do you want a game of frustration' and I'd be like 'how did you know' ...um so when you look at things like that you think they're not just looking for the bad things they're looking for the good as well and are willing to work with you (P11, Line 716)

in my head now ...its building up friendships ...cos I don't have much of a social life ...I have friends in the mental health system um you know and it's very difficult meeting other people outside of that cos I don't work and cos of lack understanding about what I do to myself cos a lot of my scars are very visible ... it's very easy to stick with the comfort zone cos these girls see the scar on my neck they're not going to freak cos they understand (P11, Line 1391)

3. Holding the hope and motivation to be different

It became very difficult after a while to lie to them (staff) ...to start with I would ...'Yeh I'm fine I just need some fresh air' and I did go out and I got myself in a bit of trouble um and then I'd come back and after a while I started to feel that not only was I letting myself down I was letting staff down as well who were doing their best to help me and there was me going behind their backs and lying to them and after a while I started to feel quite bad about that, guilty you know (P11, Line 1126) *Relationships as motivation to change*

it was so hard you know cos I didn't want to let everyone down saying 'No I'm not doing that but forcing myself to do it (P11, Line 1185) *Relationships as motivators*

4. Communication and fostering trust

I felt like we could be more open with each other... I was more open about what I was thinking or feeling or you know compared to others places where you know the nurses won't notice stuff and occasionally you get to sign a bit of paper which they say is your care plan (P11, Line 24)

I tried asking my psychiatrist (about diagnosis) but I didn't get anything that made any sense he just talked in doctors talk and I used to be like ...there's no point talking to you cos I don't understand a word you're saying ...all this doctor jargon (P11, Line 601).

also you just being totally honest and keeping ...and there are things that you can't avoid in life like traffic jams but like in the relationship I have with my psychologist ...if she really can't arrange to get to an appt she phones me and lets me know she doesn't just leave me waiting – she plans in advance (P11, Line 1488)

5. Impact of relationships to other women

between us all the girls we used to share information like that ...'your best bet is to put something down like that ..'you know fill out that form so it didn't work ...they thought it worked but obviously it didn't because we just laughed behind their backs and thought 'bloody idiots' (P11, Line 1095) *Solidarity with other women*

6. Experience and fear of abandonment

Just cos you're having a good day doesn't mean they're going to ignore you ...they don't think oh look at her she's smiling and laughing it was you still got the same time if you needed it (P11, Line 726) *Fear of what might happen if you get better*

sometimes I felt like a fraud cos if you had good days and you were in the secure unit before they'd be like there's nothing wrong with you ...nothing wrong with you at all... (P11, Line 747) *Fear of losing support*

I had a psychologist who I thought was fantastic to start with and then I'd be waiting in the room for her and I'd go up to staff and say 'look I've been waiting half an hour – where is she?' and they'd be like 'Oh she's gone back home and I'd be like 'what do you mean she's gone back home' – 'she's gone back to XXX' and I'd be like 'Oh she's gone back to XXX – just like that – over night – but she was here a couple of days ago' and they were like 'Oh well you know she didn't quite like it here.' (P11, Line 1006).

I used to categorise them (psychologists) all in the same ...yeh in the same book ...yeh you're only going to leave me anyway ...once it gets difficult for you you're only going to get up and walk away (P11, Line 1019)

1. Being an active participant

For me it means more involvement on my part um and a set ...well not always set but working alongside professionals the nurses and actually having a say in my mental health needs ... being allowed to disagree and or agree with something instead of letting them do all the work and me not being involved (P11, Line 14)

it was a lot more about involvement on both parts um and they didn't really let it go –if you didn't want to be involved it wasn't a choice as such you know ...I mean it could have been but it would have delayed the process of moving forward (P11, Line 51)

I get more say with the medication side of things and I have a very good relationship with my care coordinator who I can phone up when ever I want and the staff are up here and I am still part of here so I can have a bed overnight in a crisis or they come down and visit me ...sometimes we might go out for a coffee or sometimes we might just stay in doors and let me talk (P11, Line 352)

No-one actually told me I just saw it written in a manager's report (BPD diagnosis) when I was going... no-one told me it was something I read on a piece of paper when I was sectioned (P11, Line 572) *Not being included as active participant.*

it was a support worker when I was on a 1:1 ...I said look do you know anything about this personality disorder and she said well yeh I know abit and said well can you tell me what it is and um she told me what she knew and she suggested a book which she brought in for me and then I was able to ask a lot more questions cos I had a much better knowledge ... instead of just seeing it as a word being able to know what it means and that for me was very important to know you cos before hand knowing that they'd been discussing it between themselves and it was written in bits of paper and me having no knowledge to actually being able to question the doctor in my care ...yeh that helped hugely (P11, Line 607)

in XXX I was more involved in the discussion about why they didn't want me to go out ...uncomfortablethat was a better word ...I'm not comfortable with you going out XXX we're concerned for your safety whereas the other place was like 'you're not going out, end of story' not because of any reason they didn't give you any reason ...that was it ...and I was like 'well why aren't I allowed out' 'cos you're not –there's no section 17 leave' and that was it ...it made you worse (P11, Line 1109)

2. Role of medication

sometimes I think I disagree with the use of medication more in the general psychiatric system ...as soon as you get admitted you're handed a couple of blue pills and you're like 'what's this then' and they're like 'oh nothing just two tiny little pills' and two minutes later you're zonked out you know on larozone...and you can't sleep and you're given zolpidem ...and you're given these addictive medications and it takes a long time to come off them (P11, Line 941)

when I look in my pill box each morning and evening ...and I think 'you don't really need those XXX' - but they are so physically and mentally addictive but some of them I know that without out them I would just go back down hill (P11, Line 964)

the other thing is that I get fed up with lets try this with this, the swapping of pills ...obviously I would prefer to be on no medication ...I guess it has helped me calm down a lot more and maybe I don't act so much on my thoughts and at first I thought how does the medication help you to do that but it did ...well I say it did ...its very difficult to prove that 100 percent (P11, Line 970)

3. Taking control and making choices

I used to get frustrated at times cos no-one understands what I'm trying to tell them you know or just really feel like I can't do this at the moment but looking back I realise if I hadn't moved in to this place I wouldn't be anywhere near as involved in my care (P11, Line 60) *Being ready or not?*

I'd been used to 2 years of having someone following me ...I was scared ...I was scared about what I might be capable of doing to myself ...you know (P11, Line 135) *Fear of having control*

it didn't take me too long before I was able to say 'I don't want my razors and I don't feel safe with them at the moment ' they would help me with it whereas I'd not been used to that in the past they'd just been taken off me and that was that (P11, Line 160) *Making positive choices*

it had been so engrained into me that I wasn't allowed to do this I wasn't allowed to do make decisions whereas now I'm in unit where I am allowed to make a decision I decide when I want a cup of tea not you (P11, Line 173)

I did approach them and say you know I'm scared to have a razor on my own and we worked through that (P11, Line 191) *Making positive choices*

ok XXX you're feeling really bad but your mum's at the door do you want do you want her to come in and see you or... little things like that helped... most of the time I would see her and I was able to be more honest 'you know what mum I'm not feeling good today I'm struggling ...yeh (P11, Line 313)

there's so many years I've wasted where I haven't been ready for it but now I am ready for it (P11, Line 413) *Ready to move on*

before I went into XXX everything was taken off you and I actually caused myself more harm ...I mean they took everything off me and I did some ...the worse thing ...I set myself on fire... I don't remember much about the incident but I think that maybe if I'd had more responsibility I wouldn't have done such an extreme thing (P11, 454) *Lack of choice*

I had cut my throat seriously and so I was obviously bleeding out ... it must have been a split second but I sat there and I actually had a choice ...do I just lie here and bleed out and die or do I knock on the door and try and get some attention and some help. And urr I think that's the only time in my life where I've been in that situation and where I genuinely 100% have been in total control over life and death and whatever reason although you really want to be dead XXX... you don't ...deep down you really don't and although it was obviously there was huge risk it was ... my turning point (P11, Line 75) *Making a positive choice*

I think that the fact that they had given me control also gave me the mental control that I knew that they could have found me dead in the bathroom whereas the chances of that anywhere else would have been very slim as there were a lot more people around obviously it was very traumatic but also I really huge step forward (P11, Line 511)

there was this nursing assistant ...she waved this game under me one day called 'frustration' and I told her 'what for' (laugh) I wasn't always nice but she said – 'Now sit down and if you don't like it then you can carry on kicking the doors' so I thought alright then and I sat down and I must admit you know beforehand there was probably a chance that I would hurt myself ... but I sat down and an hour later I was still playing this game. (P11, Line 690) *Making positive choice not to self harm*

although XXX was a medium secure - you couldn't just stand up and walk out but back then ...if you insisted you were going for a walk ... rather than just unlocking the door and letting me go they'd be 'well lets just have 10 minutes talking and then you can go ... that's all sit down and talk'... but when I was at the private clinic it just wasn't even an option and I think that contributed a lot to my aggressive behaviour (P11, Line 1052) *Lack of choice making things worse*

4. Being thwarted

all they did was pick me up ...you know restrain me and carry me across the car park into the secure unit there and took all my clothes off they didn't even let me undress whereas when I went to the other place (P11, line 86) *Use of restraint*

if things were really bad the staff wouldn't even tell me that my mum would have come to visit me and they would turn her away saying 'no you can't visit your daughter today she's too unwell. They wouldn't even tell me she'd been to visit (P11, Line 306) *Not allowing access to support*

when they physically restrain you ...at the worse where they restrain you and inject you ...at the worse that was happening up to 5 times a day (P11, Line 525) *Use of restraint*

cos it was a DBT unit you had to give reasons why you wanted to go out to the garden ...and I'd be like 'cos I bloody well want some fresh air' and they'd be like 'no its got to be more than that' you have to explore why – you want to feel the wind in your hair ...you want to hear the birds and I was like 'I don't I just want to go outside and get some fresh air cos it's a nice day outside and its bloody hot in here cos you've got no windows open...(P11, Line 1075) *Having to play the game*

5. Developing a sense of self

you were able to learn to become someone and not just a number ...for so many years it felt like I wasn't a human being (P11, Line 75)

I hadn't even been allowed out in the garden or stuff like that and I had become so used to living in a bedroom ...with you know 'you need to get up now and if you don't you'll miss your cup of tea' that type of thing and Um and so it felt I had to learn a bit like a child ...I had to learn to crawl and walk you know and it was very much like that cos I didn't really know how to talk to people when I moved on as everything revolved around mental health and my diagnosis and um my self harm or just things that I did (P11, Line 112)

they let me have my lighter back, razor back, you know I was allowed to go into the kitchen and make my own cup of coffee and I was allowed it hot you know not luke warm I could drink out of a proper cup rather than a plastic one but you know it took me months before ...I used to have my own plastic cereal bowl and mug from when I was in the private clinic and I used that and they would always say you don't need to do that anymore XXX the cupboard is open is not locked you can go and get a plate or a bowl (P11, Line 138) *Becoming normal*

I know what to do if I'm having a bad time ...I know what's out there and what I can do if things are feeling bad um I struggle with things that are good. (P11, Line 332) *Know how to function in an illness identity*

you know it's not my whole - like I'm not XXXX the self harmer and personality disorder (P11, Line 816). *Developing identity outside PD*

there was a lot more um focus on that on doing positive things but when you've got PD it's very difficult to make yourself enjoy things...'oh no I've had fun today' and sometimes I'd punish myself cos I had a good day cos I felt like I was bad I'm not entitled to have a good day (P11, Line 1164) *Seeing self as deserving*

being in the system as long as I have I've got to know a lot of people ...a lot of women ...we've all been diagnosed with the same thing and yet behave very differently ...but I just feel so passionately about mental health ...and want to present it in a positive way (P11, Line 1364) *Developing a positive identity*

1. Meaningful occupation

I've been referred for this through my care coordinator to an occupational...not a therapist ...but somewhere in XXX which can help me go to college or find some kind of voluntary work just to get me out of the house (P11, Line 404)

i want to work in mental health but i want to work in the promotional side of itlike I want to do talks...like I do talks at the local university ...I lecture the student nurses and stuff and that's where I want to go ...I want to travel around the country and educate professionals (P11, Line 1288)

it is hard at the moment cos being unemployed for me it's embarrassing and really shameful for me personally I don't know ...some people think it's great ...but I'm not proud that I'm on benefits I'm really ashamed of it ...but you have to take a step back and say 'well it's not your fault' (P11, Line 1314) *Impact of no meaningful occupation*

I think if I could get up on a Monday morning and be like most people and some days you get up and you're fine and some days you wake up and think I don't want to go to work today – I think that gives you morning meaning to life and also makes you part of society again cos I'm paying my way and if I'm paying my way in life I have a right to complain whereas now I feel like I don't have that right (P11, Line 1320)

It's also important to me that I do something that I enjoy to look after myself mentally cos I've done some jobs that I've done cos I just had to cos I hated it so much cos of the way I am it didn't take long before my mood just goes and then I'm ill again (P11, Line 1336). *Occupation needs to be meaningful*

No offence to someone who works in MacDonalds but if they said work in MD's I wouldn't last that long there I need to be doing something that gives me some satisfaction and makes me feel like I'm doing something good I've done something worthwhile (P11, Line 1409)

2. Looking after others

A lot of people come up to me afterwards and shake my hand (after giving a talk) ...I can't take compliments very well but I can go home and think 'OK I've done something worthwhile today ...I've helped someone out maybe someone will think twice before they treat someone ...if I've said one word that makes one difference then it's all worthwhile (P11, Line 1451).

3. Impact of diagnosis

I was like 'What does psychotic episode mean? And what does ...' I had some kind of psychosis thing but personality was in there as well and I thought what the bloody hell's a personality disorder you know and then for a while I couldn't get my head around this personality disorder label... and I thought oh people like me they'll just give them that label cos we haven't got a clue what's wrong with them (P11, Line 579). *Negative*

not that I want a ...to be labelled as anything ...but I think it then became easier to explain to my family and you know people outside of mental health why I was like I was that it wasn't my fault but I think more for myself cos then I could work on that rather than 'Oh my god I'm going mad I'm going crazy ' ...knowing what was really wrong with me what I did what I did I just used to call myself mad before cos I didn't have any other way of describing how I was feeling (P11, Line 654). *Helping understanding*

I don't know if it was because it was a new thing but friends and family they would kind of think 'oooh what's this personality disorder you must be freaks' I didn't tell a lot of people initially because I was bit scared about how people were going to react (P11, Line 810) *stigma*

Yeh it actually made sense ...I mean when you look up the term personality disorder and you see the traits of someone with a personality disorder I think to be honest we could all tick a couple of those boxes ...but yeh when you look at it and you think – yeh I do hate myself I do think I'm worthless and in a way if you add them all up and bundle them up – that is what I am (P11, Line 836) *Helping make sense of experience*

1. Seeking self understanding

In a way I always wanted to know what was wrong with me ...It was the same as if I had a physical ailment I wanted to know what is it that's causing this pain ...and it's the same with my mental health ...what's causing this extreme pain mentally (P11, Line 553).

trying figure out where it stems – one struggle for me was was I born like it or was it because of my upbringing and my experiences in life and I don't know sometimes it would be easier for me if it were just a chemical imbalance and I was born like it I think that would be a lot more easier to explain to people ... but I think I would prefer it if someone said its OK its not cos of what you done its not cos of things that happened in your life ...you one of those people where the chemicals in your brain don't do what they should do and they're unbalanced ...I think that would be easier for me ...I think its that I would be able to discount the bad things that happened to me in my life like my childhood, my upbringing the whole way I hate myself so much why I feel so different (P11, Line 845)

2. Defining recovery

I didn't hear or have a full understanding until I went into the women's service (P11, Line 4)

that was probably the start of my recovery in a sense...teaching me...getting me back into being responsible (P11, Line 170)

I'd be really hard on myself – well I want to be there – 'yes but XXX its like a ladder and you've got to climb it and sometimes you'll get to the fifth step and you'll go back a couple but you'll get there. I'd be but I want to be there now and they'd say yeh but it just doesn't work like that um and there was many ups and downs that ladder. (P11, Line 239) *Recovery as a process*

more recently I've taken a few steps back and part of me goes back to the days when I think ah this is just hopeless but now maybe if I get through the really bad time

...whichever way they may be –negative or positive um I kind of realise I can still get back up whereas before I would think this is ridiculous I can't go on (P11, Line 415)

Recovery as a process

god I often would say to people 'fix me can you fix me' and obviously that's not that easy and you know I think I'm now still in recovery I'm not recovered it's not all gone away ...I mean I'm certainly a lot more steps up that ladder than I ever thought I'd be and maybe I'll be climbing that ladder for the rest of my life (P11, Line 777). *Recovery as a process*

3. Understanding self harm

with the self harm I've done that ever since I was a little girl ...that had never really been covered with me until ...well positively not till XXX but it also helped me understand why I do it cos there's this whole thing 'Oh self harmers they're just attention seeking' ...you know what I mean... it's such a difficult one to express 'No its not about that ' for such a long time I thought maybe ... I'm not attention seeking ... a lot of people are like 'of course you can stop it ' but I'm like 'I can't, if I could do you think I really want to keep on cutting myself or whatever' it's not the most pleasurable thing to live with (P11, Line 668)

a big one for me is self harm and the reasons people do it and the difference between suicide and self harm you know how there is such huge differences ...but people still don't see it ...I have had it where I've been sectioned because I've self harmed they've been like 'you've cut yourself you wanted to die didn't you and I'm like 'No I cut my arm it didn't mean I wanted to die (P11, Line 12

Appendix: Participant feedback form

XX July 2011

Dear participant

Thank you for taking part in my research study exploring recovery in women, diagnosed with a personality disorder in secure settings. I am very grateful for your time and the personal experiences you shared. I am now writing with a summary of my findings.

A total of thirteen women were recruited from two NHS secure facilities, XXX and XXX, and one private facility, XXX, who then took part in a semi structured interview.

I used a qualitative approach to analyse the perspectives you shared. This is called Interpretative Phenomenological Analysis, which particularly focuses on people's experiences and how they are understood.

I combined the information everyone shared with me, and I identified five main themes that summarise your experiences of recovery. You may find that you only identify with some of these conclusions.

The first theme concerned the way in which people understood recovery and the fact that it can seem like a journey, with progress and setbacks.

Relationships were seen as very important and people shared the qualities that helped develop good relationships such as the experience of being cared for, feeling known and understood, the importance of good communication which helped build trust, and the value of other people holding on to hope and providing motivation to change. Relations with other women could be a source of support but they could also be difficult due to managing other's distress. There was also a fear of being abandoned by services before people were ready.

Assuming responsibility your own care was seen as very important for recovery and included being an active participant, taking control and making choices, and being able to decide when you are ready to move on. People had mixed views about the value of medication but being included in decisions about medication was valued. Sadly a number of incidences were shared where people were not supported in taking responsibility through poor communication, lack of respect and care, and the use of restraint and seclusion.

Evolving a positive identity through taking part in meaningful activities was seen as important and being able to care for others, such as older people, children and animals, was mentioned by many participants. The stigma of the personality disorder was seen to work against developing a positive identity.

Forming a meaningful understanding of the mental health experience seemed to also be important. Therapy and the framework of the diagnosis seemed to help people better understand why they experienced difficulties. Being able to explain why people self harm also seemed to be important.

What you shared helps shed light on our understanding recovery in women with personality disorders in secure settings. Your descriptions highlight what is needed in services and in further research. These results suggest that it may be important to provide more client and

staff education about recovery, the reasons that some people come to be diagnosed with a personality disorder and the reasons why people self harm. Being more creative in finding ways to increase access to meaningful activities as well as opportunities to be part of decision making wherever possible is something that professionals need to be mindful of.

These findings fit with government directives to take into account what matters to service users (No Health Without Mental Health, Department of Health, 2011). I will be sharing them with the services involved in my study, and will submit the findings to a peer-reviewed journal.

Thank you again for taking part in this study. Please do not hesitate to contact me in the next two weeks on the above number if you have any questions or would like to respond to the findings.

Yours sincerely,

Julia Jenkinson

Trainee Clinical Psychologist

Appendix: Report for ethics and R&D

XX July 2011

Dear _____

I am writing with a summary of my research project findings:

Project Reference Number: 10/H0703/61

Project Title: Exploring recovery with women, diagnosed with a personality disorder in secure settings.

The study started in January 2011 and was completed on XXX July 2011. The aim of the study was to explore how women, diagnosed with a personality disorder, in secure settings came to define and understand their own recovery and to consider how recovery may be supported or undermined for this group of women. A total of thirteen women were recruited from two NHS secure facilities, XXX and XXX, and one private facility, XXX. Research and Development approval was obtained before approaching the participants. Six participants gave sufficiently detailed interviews for analysis using Interpretative Phenomenological Analysis, a qualitative methodology designed to explore lived experience.

The analysis led to the identification of five master themes and composite sub-themes: Recovery which comprised 'defining recovery' and 'recovery as a journey'; Centrality of relationships which included 'experience of care', 'being known and understood', 'communication and trust', 'holding hope and motivation for change', 'relating to the other women', and 'fear of abandonment'; Assuming responsibility which comprised 'being an active participant', 'taking control and making choices', 'being ready – who decides?', 'role of medication', and 'being thwarted'; Evolving identity which included 'developing a sense of self', 'meaningful occupation', 'self as carer', and 'impact of diagnosis'; and Understanding the mental health experience which comprised 'seeking self understanding' and 'understanding self harm'.

There is currently no published literature exploring personal recovery in individuals diagnosed with a personality disorder nor on the personal experience of recovery for women in secure settings. This study sheds light on the impact of secure settings on recovery for women and also the way in which a diagnosis of personality disorder affects the recovery process. A number of the identified themes, such as assuming responsibility, relationships and meaningful occupation, resonated with published research exploring recovery in men diagnosed with schizophrenia in secure settings. However issues, such as a fear of losing support undermining the recovery process, the tension of who decides when the individual is ready to move on, the impact of being in close confinement with similarly distressed women and the lack of understanding of self harm seem to be particularly salient for this group of women.

Clinically the findings suggest that greater education to promote better understanding of the concept of recovery, the aetiology of personality disorder and the function of self harm, amongst staff and service users would be extremely helpful to facilitate better staff-service user relationships within which recovery could be encouraged. Greater staff support seems essential to prevent burn out and the loss of hope when working with this client group.

Given the governments commitment to developing gender specific services a comparative study examining the recovery needs of men and women may help in designing more effective services, including those designed to support individuals leaving secure care.

The findings of this study will be shared with all the participants and with the NHS Trusts and private facility that hosted the project. They will also be submitted to a peer reviewed journal for publication.

Please do not hesitate to contact me if you have any further questions.

Yours sincerely

Julia Jenkinson

Trainee Clinical Psychologist

Appendix: Search Strategy

Search Strategy for Part A

The following procedure was followed to identify relevant literature.

(1) Literature searches were conducted on the following electronic databases: PsychINFO, (1985- 2008), Medline, Web of Science, and Cochrane Library, (1986-2008).

(2) The following search terms were used:

- personality disorder and secure units/settings/care

- recovery and personality disorder/borderline personality disorder

- recovery and secure units/settings/care
- recovery and personality disorder/borderline personality disorder and secure units/settings/care
- women and secure units/settings/care
- women and recovery

(3) Article abstracts were reviewed for relevance.

(4) References of relevant articles were examined for additional papers.

Appendix: Consent form

Version 2 – 25.8.10

PARTICIPANT CONSENT FORM

Exploring Recovery in Women with a Diagnosis of Personality Disorder in a Secure Setting: A Service User Perspective

Thank you for agreeing to take part in the above study. Please read the following statements and sign underneath if you are happy to do so.

(1) I have read and understood the information sheet dated 25.8.10 for the above study.

Someone has helped explain the study to me and I have had the opportunity to ask questions which have been answered satisfactorily.

(2) I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, without my medical care or legal rights being affected

(3) I agree to my care coordinator being informed of my participation in the study.

(4) I agree to take part in the study

Signed: _____ Date: _____

Appendix: Interview Schedule



Version 1 – 7.6.10

Interview Schedule

1. What does the term recovery mean to you in relation to your mental health?

When did you first hear the term? Where were you? What was your initial understanding of the term? Did the term make sense to you? Was it helpful?/unhelpful? Is there a term you would rather use – such as 'getting better' or 'learning to cope' Did anyone ever explain the term to you.

2. How would you know you were in recovery? What would that look like?

3. Has your understanding of the term 'recovery' changed over time?

Could say something about how it has changed? What factors/people have affected this? Is it now more or less helpful?

4. Do you think that your understanding of recovery is the same as the other people (staff, family friends) who are involved in your life?

Is what way is it the same? In what way is it different? Why might people see it differently? How do these different views affect you?

5. What do you feel is most important to you to help support your recovery?

What helps in the secure setting as opposed to in the community? Which people do you find helpful and why? What are your main coping strategies and how are these recognised? What role does therapy play/not play in your recovery?

6. What makes recovery more difficult for you?

What are the factors in the secure setting which serve to undermine recovery? Is this the same/different to influences in the community?

How well have you been able to communicate with people about the things that you find unhelpful? What has the response been?

7. What information have you been given about your diagnosis?

What was the impact of this diagnosis? In what way was the diagnosis helpful/unhelpful? Did you experience it as stigmatising? Did it help with accessing services? Did you accept the diagnosis?

8. How does a placement in a secure unit promote or prevent recovery?

Are secure placements compatible with recovery? Do you feel that your placement was necessary/ supportive of your recovery? How can staff and therapists better support recovery of women diagnosed with PD in this setting?

8. (Only relevant for some women)

Appendix: Information sheet

Version 2 – 25.8.10

PARTICIPANT INFORMATION SHEET

**Exploring Recovery in Women with a Diagnosis of Personality
Disorder in a Secure Setting: A Service User Perspective**

I am a trainee clinical psychologist currently undertaking a final year research project as part of a doctorate in clinical psychology at Salomons (South Thames Clinical Psychology Training Scheme, part of Canterbury Christ Church University College). I would be very grateful if you would consider taking part in my research study. Before you decide whether you would like to take part or not, it is important for you to understand why the research is being done and what it will involve. Participation in the project is entirely voluntary. Please take time to read the following information carefully.

The research project has been approved by East London Local Research Ethics Committee and Sussex Partnership NHS Trust.

Purpose of study

The term 'recovery' is widely used in adult mental health. It refers to the process of feeling better or learning to cope better with mental health difficulties. This study aims to explore what recovery means to women who have been given a diagnosis of personality disorder and have been placed in a medium secure unit. It aims to identify the strengths and limitations of current recovery approaches. It will examine how recovery approaches may need to be developed for this group of women to give them more hope for the future.

Participants

I will be seeking to recruit women who have been given a diagnosis of personality disorder at some point in their mental health history and who have experience of being in a medium secure unit. I will be inviting participants to take part in a one to one discussion about their experiences of recovery – both good and bad.

What will the research involve?

I will meet with potential participants to introduce the project and give the opportunity to ask questions. Interested individuals will be given an information sheet and consent form and given a further opportunity to ask questions. If you feel it would be helpful I can arrange for someone on the unit to read through the information with you.

Individuals who agree to take part will be asked questions about their experience of recovery. It is expected that the discussion will last between 60 -90 minutes but this will depend on how much you wish to say. The meetings will take place at the unit. The discussions will be tape recorded to make sure that an accurate record is kept. The discussions will be analysed to identify information that may help to improve the way that clinical psychologists work with this group of women. I will make

arrangements to feedback the findings of the research to you – this may be done in person or in writing depending on your preference.

Confidentiality

If you decide to take part, your name and any other identifying information will be kept strictly confidential. The recordings of the discussions will be typed up and stored on a computer. All information on the computer will be made anonymous and password protected. Only I will know the identity of the person in the discussions. Your care coordinator will be informed that you have agreed to participate in this study but your GP will not be informed.

There are limits to the confidentiality. If you shared information that causes me to be concerned for yours or someone else's safety I would share my concerns with you and discuss the need for me to have a discussion with your care coordinator.

What will happen to the information shared in the discussion?

The tapes will be stored in a locked cupboard and erased once the research has been completed. Password protected CD's of the written copies of the discussions will be kept in a locked cabinet at Salomon's and destroyed 10 years after the research has been completed. It is my intention to write up the research for publication and one of the requirements of this is that paper copy of the discussions be kept for five years in a locked cupboard after which time they will be destroyed. In the write-up of the research, extracts from individual written discussions may be included but any information that could identify you would be removed.

What would happen if I decided to withdraw from the study?

In the event that you no longer wanted to take part in the study all the information collected would be destroyed and would not be used in the research. You would not have to give an explanation of your decision and it would in no way affect the care provided to you.

Indemnity Insurance

In the unlikely event that something goes wrong and you feel that you have been caused unnecessary physical or emotional distress during the research, if this was due to someone not doing their job properly, then you may have grounds for a legal action against Christ Church Canterbury University but you may have to pay your own legal costs. The normal National Health Service complaints procedure will also be available to you.

Complaints

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal NHS complaints procedures will be available to you. You can also contact myself or Dr John McGowan (Clinical Psychologist) on Tel: 01892 507673.

Should you at any point wish to discuss issues raised by your involvement in the study, a message can be left for me on 01892 507673 and I will be happy to call you back.

Contact details

Please feel free to contact me if you have any further concerns or queries:

Julia Jenkinson, Salomons Clinical Psychology Training
Scheme, David Salomons Estate, Broomhill Road, Southborough, Nr. Tunbridge Wells,
Kent, TN3 0TG. Tel: 01892 507673.

Thanks for taking the time to read this.

